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PHILOSOPHICAL, LEGAL, AND SOCIAL ASPECTS OF SURROGATE DECISIONMAKING FOR ELDERLY INDIVIDUALS

Contractor Documents

May 1987

Surrogate Decisionmaking for Elderly Individuals who are Incompetent or of Questionable Competence, Allen Buchanan, Ph.D., Department of Philosophy, University of Arizona, Arizona; and Dan W. Brock, Ph D., Department of Philosophy, Brown University, Rhode Island.

Withholding and Withdrawing of Life-Sustaining Treatment for Elderly Incompetent Patients: A Review of Court Decisions and Legislative Approaches George J. Annas, J.D., M.P.H; and Leonard H. Glantz, J.D., Boston University Schools of Medicine and Public Health, Massachusetts.

Legal Perceptions and Medical Decisionmaking, Marshall B. Kapp, J.D., M.P.H, Department of Medicine in Society, Wright State University, Ohio; and Bernard Lo, M.D., Department of Medicine, University of California at San Francisco, California.

Philosophical Issues Concerning the Rights of Patients Suffering Serious Permanent Dementia, Ronald Dworkin, Department of Philosophy, University College, Oxford, England.

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SURROGATE DECISIONMAKING FOR ELDERLY INDIVIDUALS WHO ARE INCOMPETENT OR OF QUESTIONABLE COMPETENCE

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Although the principal author of this study is Allen Buchanan, substantial contributions were made by Michael Gilfix, Dan W. Brock, and Deborah Mathieu as well. Gilfix, an attorney who specializes in serving elderly people and their families, contributed especially to chapter 4. Brock is the author of the greater part of the analysis of competence in chapter 2. Finally, Mathieu contributed to the substance and organization of the work as a whole.

EXECUTIVE SUMMARY

Some of the chief results of this study are presented here in necessarily abbreviated form for emphasis; it is important to note that they are elaborated and justified in the body of the work. These conclusions and recommendations are only those that are of the most fundamental importance.

The problem of decisionmaking for incompetent or questionably competent elderly people is one of the most serious issues now facing Americans and people in all other industrial countries.

Competence is decision-relative, and is to be understood as decionmaking capacity. A competence determination is thus a determination of a particular person's ability to perform a particular decisionmaking task at a particular time and under specified conditions. Decisionmaking capacity has three chief elements: communication and understanding, a relatively stable set of values or a conception of the good, and reasoning and deliberation.

No single standard of competence is adequate for all decisions. The standard depends in large part on the risk and on the complexity of the information involved. The greater the risk and the more complex the information to be evaluated, the higher the level of decisiomaking abilities required. The potential for conflicts of interest in decisions about financial matters and living arrangements is so serious that adequate protection of the individual generally requires judicial determinations of competence for such decisions. Determinations of competence to make decisions about medical treatment generally need not involve judicial proceedings.

Although determinations of incompetence to make medical decisions need not routinely be accomplished through formal court proceedings, coherent institutional policies are needed within hospitals and nursing homes to ensure that incompetence is determined in an ethically and legally sound way. If they are to provide an adequate substitute for judicial determinations, such policies will:

- articulate standards and operational criteria for determining competence,
- fix responsibility on someone in the institution for establishing whether a given person is competent or incompetent to make certain decisions,
- include effective safeguards against abuse or error, and
- provide guidance as to when court intervention is appropriate.

Considerable evidence exists of widespread confusion, error, and abuse in the formal legal procedures by which elderly individuals are determined to be incompetent to manage their own affairs, and by which surrogates are designated for them. To help remedy these defects, the following safeguards ought to be instituted.

- The subject of a guardianship or conservatorship hearing must be notified of the hearing and of the right to appear at it.
- The hearing may not proceed without the presence of the individual in question unless that individual has submitted a notorized statement waiving the right to appear, or there is well-documented evidence that the individual is unable to attend because of the potential of serious harm to him or herself, or there is well-documented evidence that the individual's attendance would be meaningless because of his or her level of incapacity.
- Those who petition for a determination of incompetence must bear the burden of proof that the least restrictive alternative is being taken.
- Reasonable efforts must be made to restore or enhance competence where possible (e.g., through better medical treatment, nutrition, etc.).

- Evidence of lack of appropriate decisionmaking ability must be provided from sources not likely to be biased by conflicts of interest.

The most fundamental principles constituting a theory of surrogate decisionmaking are the following:

- Ethical Value Principles, specifying the basic values that are to secured in dealings with incompetent individuals;
- Guidance Principles, giving direction in deciding for incompetent individuals (these included the Advance Directive Principle, and the Best Interest Principle);
- Authority Principles, specifying who is to decide for the incompetent individual; and
- Intervention Principles, specifying the conditions under which the decisions are to be taken out of the hands of the surrogate decisionmaker.

Guidance principles for surrogate decisionmaking can conflict, and therefore priority rules for ordering them are needed. A consensus is emerging in the law and in the bioethical literature on the following order. In general, a valid and clear advance directive takes precedence; if there is no advance directive, then substituted judgment is to be applied; if this too is inappropriate, the best interest principle is to be invoked.

There are important limitations in the utilization of each of the guidance principles. Although a competent person has the right to refuse life-sustaining treatment or care, it does not follow that the same choice always is to be respected if embodied in an advance directive. Morally significant asymmetries between the contemporaneous choice of a competent person and the issuance of an advance directive can warrant limitations on the authority of the latter that would not be appropriate for the former. It may sometimes be appropriate to refuse to implement an advance directive when doing so would result in the death of an individual who, though incompetent, would with proper care and treatment lead a life that clearly contains more pleasure and enjoyment then suffering and pain — especially if such a situation was not anticipated by the individual's advance directive. Substituted judgment cannot be exercised if the person for whom the decision is to be made never was competent. This principle also is not applicable to situations in which there is insufficient or contradictory evidence of what the incompetent patient would want if competent. Permanently unconscious patients are beyond the scope of the best interest principle. Continuing to treat them is of no benefit to them, and so life-sustaining systems may be withdrawn without infringing these patients' rights.

Legislation to give effect to advance directives for health care is developing rapidly. The Durable Power of Attorney for Health Care provides hitherto unavailable opportunities for comprehensive planning that can maximize individuals' control over their futures and ease the burdens of those who will care for them when they become incompetent.. New legislation concerning the Durable Power of Attorney for Health Care must address a number of complex issues:

- How is incompetence to be determined, and by whom?
- What effective penalties, if any, are to be imposed on health care providers and surrogates who refuse to follow valid advance directives (unless they seek court intervention for a determination of guardianship, or transfer the care to another provider or an alternate designated surrogate who will comply?
- Should the law provide an opportunity for the principal to sign a special form by which he or she can negate the exclusion of certain procedures (such as electroconvulsive shock therapy) from the proxy's authority, and/or waive the right to revoke the durable power of attorney after becoming incompetent? Or is it justifiable paternalism for the law to exclude such procedures from the scope of the durable power of attorney?

For medical decisions, the appropriate presumption is that the family of the incompetent is to be the principal decisionmaker. "Family" is to be understood broadly as the set of persons with whom the patient is most closely associated.

The presumption that the family is to serve as the surrogate decisionmaker is defeated under any of the following conditions: the family is incompetent to make the decision; the family member who is serving as surrogate is acting under duress; the surrogate has a conflict of interest with the incompetent patient that is likely to bias the surrogate's judgment; there is evidence of previous neglect or abuse of the incompetent by the family; or the family is disregarding the incompetent's advance directive or, where substituted judgment is applicable, the family is acting in ways contrary to the incompetent's previous values and preferences.

Adequate protection of the rights and interests of the incompetent patient with no family will in general require that medical decisions are to be made by a court-appointed guardian, unless equally effective safeguards are available within the health care institution. If such institutional safeguards are to take the place of judicial scrutiny of medical decisions for incompetents who lack families, they must include impartial discussion and review of decisions by persons who are neither directly involved in the case nor subordinates of those directly involved. Special care must be taken to ensure that the interests of the patients, not those of the institution, are the focus of the decisionmaking process. Institutional ethics committees can serve as an acceptable alternative to judicial proceedings only if their membership includes persons of diverse backgrounds who are not closely connected with the institution and its special interests.

Properly constituted institutional ethics committees can perform several valuable functions in decisionmaking for incompetents, including serving as a focus for bioethics education in the institution and the community; providing ethics consultation services for staff, patients, and family; revising and improving institutional policies; and determining which cases ought to be referred to the courts or to government agencies.

Many health care allocational decisions now are made for morally irrelevant or inappropriate reasons (e.g., the family's guilt or the provider's interest in preserving his or her self-esteem). The rational insurance (or prudential choice) approach to the evaluation of social policy choices concerning allocation can serve as a check on these tendencies by helping fix our attention on the appropriate ethical considerations. This model offers a way of thinking about the tradeoffs represented by different allocations of a fixed amount of resources from a single perspective (that of one person budgeting his or her resources for health care over a whole lifetime), without requiring or allowing one person's or group's peculiar perspective to determine what some other individual or group gets.

There are limits on the burdens a family can reasonable be expected to bear in caring for an incompetent elderly member. The family has no obligation to provide the very best care if doing so imposes excessive burdens on them or deprives them of resources needed to fulfill important obligations to other family members. The degrees of responsibility of one family member for another depends on the nature of the relationship. Obligations of grown offspring toward their aged parents are less extensive than those of parents toward their minor children or of spouses toward each other.

CHAPTER 1: INTRODUCTION

The Magnitude of the Problem

The issue of decisionmaking for incompetent or questionably competent elderly people touches us all — as individuals who have or will have friends or family members who are elderly and incompetent, as persons who are ourselves likely to be in this situation at some point during our last years, and as concerned citizens.

Incompetence may be limited or complete, chronic or intermittent, and it may be due to one or more of a diverse set of medical disorders, including: 1) degenerative neurological disorders such as Alzheimer's disease and Parkinson's disease, 2) single or multiple cerebrovascular accidents (stroke), 3) severe acute or chronic depression that impairs cognitive function, 4) temporary or permanent coma, 5) mental retardation, 6) psychosis, or 7) severe personality disorders.

The problem is especially grave for the elderly, not because advanced age itself is to equated with loss of competence, and not simply because some forms of dementia are more common among the elderly, but chiefly because the incidence of chronic illness is higher among them and because under the conditions of modern medicine many patients in the last stages of chronic illness are incompetent. Modern medicine, especially in the tertiary care setting, contributes to the magnitude of the problem in part because it has been so successful. Through the use of sophisticated life-sustaining technology such as respirators, as well as much simpler devices such as nasogastric feeding tube, medicine can prolong life — sometimes for many years — even when disease or trauma have impaired or obliterated the patient's cognitive functions.

Medical technology also plays a role in the problem in another way: Some medical interventions themselves diminish the patient's competence. Steroids and other highly toxic drugs used in cancer therapy can seriously impair mental function, and dosages of narcotics sufficient for effective relief of pain can render the patient heavily sedated if not virtually anesthetized. The use of a respirator can prevent a competent patient from voicing preferences, or from contradicting the presumption of incompetence.

The scope of the problem is clear. The elderly as a group are increasing rapidly, both in absolute numbers and as a percentage of the overall population. In 1975, for instance, there were 22 million people aged 65 or older; by the year 2000, there will be 30 million (National Institute on Aging, 1977). Table 1-1 indicates for selected years the percentage of the population that is elderly.

Table 1-1. Share of U.S. Population Over 64 Years of Age,
1900, 1940, 1960, 1975, and 2000

YEAR	PERCENT
1900	4.0
1940	6.5
1960	9.0
1975	10.5
2000	11.5

SOURCE: National Institute on Aging, Our Future Selves: A Research Plan Toward Understanding Aging (Washington, DC: National Institutes of Health, 1977).

It is not simply that there are more people over 64 than ever before; there is also a remarkable increase in those over 74, as well as those over 84. In 1950, for example, 29 percent of the elderly were 75 or older; by 1975, the number had increased to 38 percent; by 2000, an estimated 45 percent of the elderly population will be at least 75 years old

(National Institute on Aging, 1977). Table 1-2 outlines this growth.

Table 1-2. Distribution of U.S. Elderly Population by Age-Group, 1950, 1975, and 2000

Age-Group	Percent of Total Elderly		
	1950	1975	2000
65-74	71	62	54
75-84	25	30	34
85 or older	4	8	11

SOURCE: National Institute on Aging, Our Future Selves: A Research Plan Toward Understanding Aging (Washington, DC: National Institutes of Health, 1977).

By the year 2000, even if there are no improvements in mortality rates, it is estimated that there will be 12 million very old (75 or older) people. If mortality rates decline, this figure may reach 16 million to 18 million (National Institute on Aging, 1978).

Since the incidence of the two most prevalent forms of dementia — Alzheimer's disease and multi-infarct (or cerebrovascular) dementia — increases with age, these demographic changes will greatly enlarge the class of incompetent individuals unless significant progress is made in the treatment of these diseases. It has been estimated that between 10 and 18 percent of all persons aged 65 or older suffer from some form of dementia, and that between 15 and 20 percent of those 80 or older fall into this category (Jarvik, 1980). These figures have led many experts to conclude, with Sir Martin Roth, a world-renowned expert on dementia, that dementia among the elderly is "the largest and most pressing single problem facing present day health and social science in different parts of the world" (Roth, 1983).

The problem is staggering not simply in terms of the numbers of elderly individuals who are or will be incompetent, but also with regard to the types of decisions that must be made and the different sorts of settings in which those choices must be faced. Decisions often must be made about 1) medical care; 2) placement in nursing homes, mental institutions, hospice, or residential homes for the elderly; 3) the financial details of estate management; and 4) whether the incompetent individual is to participate as a subject in medical or social science research.

This paper concentrates primarily on decisions concerning medical care. Placement and financial decisions will also be discussed (though in much less detail), not only because they can have a great impact on the life of an elderly incompetent person, but also because they both influence and are influenced by decisions about medical care. For example, a decision to undertake a vigorous course of chemotherapy for an elderly patient may entail removing that person from the family home for hospitalization, whereas placement in a nursing home that lacks sophisticated emergency life-sustaining technology will limit a patient's medical options. Relatives may decide to place an elderly person in a hospital or nursing home because they lack the financial or emotional resources to provide home care. This change may be so traumatic that the elderly individual suffers a diminution of competence and a decline in health.

No attempt is made in this paper to address the important and complex ethical issues concerning medical or social science research involving those who are incompetent or of questionable competence.

Institutional Arrangements and Policy Considerations

General policy decisions define options and provide incentives that favor certain choices over others. Thus, to a large extent they determine the institutional framework within which particular decisions concerning individual incompetent elderly persons are made. In come cases, a society's refusal to make certain highly divisive and morally controversial policy choices — e.g., the decision to employ cosst as an explicit factor in decisions to terminate life support — or even to acknowledge explicitly that such choices are being made indirectly or by default, can have equally profound effects upon individual decisions (Calebrisi and Bobbitt, 1979).

In this regard, two errors must be avoided. On the one hand, we cannot simply take the institutional framework — the existing set of criteria and constraints — as an unalterable given, as if it were a fact of life utterly beyond our control, rather than a human creation. On the other hand, we must not indulge in utopian fantasies by proceeding as if the institutional framework can be modified easily and without cost. One of the main themes of this paper is the need for a complex and ethically consistent division of labor in bearing the responsibility for deciding for elderly incompetent patients.

To what extent should this burden be borne by individuals themselves in planning for their old age or by their families, rather than by social institutions? And granted that institutions will play a significant role either directly (by assuming the authority to make some decisions) or indirectly (by constraining or supporting the choices made by individuals and their families), what is the appropriate division of labor among different types of social institutions? For example, what roles should formal institutions — such as the courts — have with regard to protecting incompetent individuals? And should there be a role for less formal institutional arrangements, such as hospital ethics committees?

As important as the division of decisionmaking authority and responsibility for the elderly incompetent is the division of financial responsibility for caring for them. In one respect, the elderly in this country are the recipients of an especially large portion of social support: Medicare, although far from complete in its coverage of medical procedures, is the closest thing to an adequate publicly funded health insurance program available in the United States. In contrast, an estimated 20 million to 22 million Americans any lack form of private or public medical insurance coverage (President's Commission for the Study of Ethical Problems in Medicine and Biomedical and Behavioral Research, 1983b). Another 22 million to 25 million have coverage that is inadequate by any reasonable standard (President's Commission, 1983b). Medicaid has not solved the problem of access for the nonaged: 40 percent of those at or below the official "poverty level" are not covered by this program, and many who do qualify for it are unable to obtain services because in some areas Medicaid reimbursement rates are so far below those of private insurance that physicians simply refuse to treat Medicaid patients.

In the past, some people who lacked private or public medical insurance received free treatment through the practice of "cross-subsidization," in which hospitals used surplus resources from insured patients to absorb the costs of treating the uninsured. However, there are indications that this "hidden welfare system" is being eroded by two recent developments: the use of Diagnostic Related Groups (DRGs) and other prospective payment arrangements, and the general increase in price competition among health care institutions, both "for profit" and "nonprofit" (Brock and Buchanan, 1986). As the hidden welfare system shrinks, the problem of access widens.

These facts about the health care system as a whole have a direct and important bearing on the problems of the incompetent elderly. One of the chief complaints about the current division of financial responsibility is that although Medicare provides relatively full coverage for medical procedures for the incompetent elderly individual, many of these persons also need long-term "non-medical care," which Medicare does not cover, and that this care must be paid for by the individual or the family unless the individual is poor enough to qualify for Medicaid. When Medicare was created, long-term nursing home care was deliberately excluded, chiefly out of fear that including it would lead to runaway costs.

In an era in which concern over rapidly rising health care expenditures tends to eclipse all other considerations, including that of access to care, an extension of Medicare coverage to include supportive home care or long-term care, while preserving current levels of coverage for medical care, seems politically unlikely. Even if this is so, however, two important policy issues remain, and each involves fundamental ethical issues. The first is whether increasing access to medical care for the nonelderly who currently lack it should take precedence over efforts to sustain current levels of Medicare coverage in the face of rising health care costs in general and a rapidly growing elderly population. The second is whether efforts should be made to achieve a reallocation of public resources for the elderly by shifting funds from medical care to long-term and supportive home care.

Ethical, Legal, and Social Issues

A vast literature exists on the problems of the elderly, and much of it deals explicitly or implicitly with problems of decisionmaking for those who are incompetent or of questionable competence. However, this literature has tended to suffer from fragmentation: Ethical, legal, economic and social policy issues have not been adequately integrated.

The basic questions that must be answered are clear enough, if stated in general terms. (1) How is competence to be understood? (2) How and by whom is it to be assessed reliably? (3) Who is to decide for the individual who has been determined to be incompetent? (4) According to what substantive standards or principles are decisions to be made? (5) Within what sort of institutional framework are decisions to be made? (6) How are the burdens of caring for elderly incompetent individuals to be distributed fairly among individuals, families, social organizations, and various levels of government? Moving beyond these generalities, however, the need for a more sophisticated conceptual framework becomes evident.

The Aims and Plan of This Study

This paper's aim is to criticize, integrate, and build on previous contributions of numerous others in the medical, ethical, legal, and social policy literature, and to anchor a coherent theoretical perspective on the issues in a concrete understanding of existing institutions and practices. Chapter 2 sets out the relevant concept of competence and contrasts it with alternative concepts, which are criticized and rejected. A distinction is drawn between (1) the concept of competence as the capacity to make a decision, (2) standards for competence that vary depending on features of the decision to be made, and (3) operational criteria or procedures for determining whether the appropriate standard of competence is met in a particular case. The chapter also delineates similarities and differences in determining competence in the context of different types of decisions, from the withholding of life-sustaining treatment to estate management. Finally, the chapter addresses the issue of who ought to make the determination of competence in various contexts.

Chapter 3 sets out the basic conceptual and ethical framework for decisionmaking, once the threshold question of competence has been answered and the individual has been found to lack capacity for the decision or decisions in question. Until quite recently, analyses of key policy issues in health care, including those undertaken by government agencies, generally have avoided an explicit confrontation with the most basic ethical issues, usually in the name of the supposed value-neutrality of the social sciences, while nonetheless tacitly assuming often controversial and sometimes inconsistent ethical positions (Buchanan, 1985). This paper frankly acknowledges the centrality and complexity of the ethical issues. In doing so, we have sought to avoid two all-too-common errors of some analysts: reducing ethical questions to legal ones, and drawing false comfort from a distinction between "policy issues" and "ethical issues."

There are two good reasons for resisting the temptation to reduce ethical issues to legal issues. First, the law is itself insufficiently developed to provide sure guidance for some of the most urgent problems in this area. In particular, the law has frequently responded belatedly and inadequately to problems concerning the termination of sophisticated life systems for competent as well as incompetent patients. Even fundamental and longstanding legal concepts — including the legal concept of death have been strained and in some cases rendered obsolete by rapid technological developments (President's Commission, 1981). Where old law must be adapted to new circumstances and where new law must be developed, ethical guidance is essential.

Just as importantly, there may be weighty ethical reasons for not attempting to extend the law into some areas. Whether or not the law is an appropriate instrument for dealing with a particular problem is itself in part an ethical issue. Further, existing law, even where it does clearly apply to the problems under consideration here, cannot be regarded as fixed and sacrosanct. The law itself can and should be subjected to ethical criticism.

The second error is more subtle, but equally dangerous. It is a mistake to assume that "policy matters" and "ethical issues" can be separated neatly, especially at the outset of an analysis. Most serious policy issues involve an ethical component, though policy analysts may fail to see this because they have not made their own ethical assumptions explicit.

The distinction between ethical issues and those that only are matters of policy make sense only after a great deal of ethical analysis has successfully been completed. For example, once we have fulfilled whatever ethical responsibilities we have (both as individuals and collectively) to provide health care for those who cannot afford it, society might as a matter of social policy decide to spend a great deal of additional money on social support for the elderly. But the problem that must be solved before we could identify these further allocational decisions as being "merely" a matter of social policy rather than of ethics is the daunting one of delineating the scope and limits of our ethical obligation to provide health care for the indigent. Assuming a facile distinction between ethical and social policy matters can have unfortunate methodological consequences: Fundamental ethical issues may simply be overlooked or ethical analysis may appear belatedly as a reaction to policy rather than as a vital component of policy formation.

For these reasons chapter 3 develops an extensive ethical framework for evaluating current social policy and for developing recommendations for change. However, the ethical analysis is not restricted to social policy. It examines problems of individual ethical choice as well, and takes as one of its fundamental tasks the problem of demarcating the proper boundary between matters of individual choice and responsibility, and those of collective responsibility and social policy.

Chapter 4 is a selective presentation of the most important current practices and institutions that shape decisions for elderly incompetent patients. This chapter emphasizes, in more concrete detail, the wide variety of decisions that now are made, and the diversity of decisionmaking settings in which they occur. It contains descriptions of what actually occurs — both formally in the courts and through less formal but more pervasive decisionmaking practices — but is not restricted to pure description. Existing practices and institutions are described in order to identify the most important problems and to expose the most serious defects of current social arrangements.

Chapter 4 also applies the ethical principles developed in chapter 3 to these problems and defects. Although no attempt is made to offer detailed recipes for the future, some basic conclusions are drawn, and a set of more or less concrete recommendations is offered.

CHAPTER 2: COMPETENCE AND INCOMPETENCE[*]

Discussions of competence often have been hampered by a failure to distinguish carefully among the following questions:

- What is the appropriate concept of competence?
- Given an analysis of the appropriate concept of competence, what standard (or standards) of competence must be met if an individual is to be judged to be competent?
- What are the most reliable operational measures for ascertaining whether a given standard of competence is met?
- Who ought to make a determination of competence?
- What sorts of institutional arrangements are needed to assure that determinations of competence are made in an accurate and responsible way?

Each of these questions shall be addressed separately. This chapter — which is concerned with the theoretical underpinnings of determinations of competence — will concentrate on the first three questions. The last two, which raise more practical and concrete concerns, can only be addressed in detail after the ethical framework of chapter 3 has been laid out and the realities of current practices have been described in chapter 4.

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[*] The analysis in this chapter develops in a more systematic and concrete way the account of competence and incompetence, of which Brock was the principal author, in President's Commission for the Study of Ethical Problems in Medicine and Biomedical and Behavioral Research, Making Health Care Decisions and Deciding to Forego Life-Sustaining Treatment, and in a discussion paper on competence by the Commission.

The Concept of Competence

Competence as Decision-Relative

The statement that a particular individual is (or is not) competent is incomplete. Competence is always competence for some task — competence to do something. The concern here is with competence to perform the task of making a decision. Hence competence is to be understood as decisionmaking capacity. But the notion of decisionmaking capacity is itself incomplete until the nature of the choice as well as the conditions under which it is to be made are specified. Thus competence is decision-relative, not global (President's Commission, 1982, 1983a). A person may be competent to make a particular decision at a particular time, under certain circumstances, but incompetent to make another decision, or even the same decision under different conditions. A competence determination, then, is a determination of a particular person's capacity to perform a particular decisionmaking task at a particular time and under specified conditions.

Any individual may be competent to perform some tasks (e.g., drive a car), but not others (e.g., solve differential equations). The tasks relevant to this paper vary substantially, and include making decisions about medical treatment, entering into contracts, deciding whether to continue to live on one's own in an unsupervised setting, and so forth. It is true, of course, that for some individuals, decisionmaking capacity is entirely lacking (for instance, when the individual is permanently unconscious), but these are the unproblematic cases.

Decisionmaking tasks vary substantially in the capacities they require for performance at an appropriate level of adequacy. For example, even restricted to medical treatment decisions, there is substantial variation in the complexity of information that is relevant to a particular treatment decision and that consequently must be understood by the decisionmaker. There is, therefore, variation in what might be called the objective demands of the task in question — here, the level of abilities to understand, reason, and decide about the options in question. But there is also variation of several sorts in a subject's ability to meet the demands of a particular decision. Many factors that diminish or eliminate competence altogether vary over time in their presence or severity in a particular person. For example, the effects of dementia on a person's cognitive capacities is at some stages commonly not constant, particularly in cases of borderline competence. Instead, mental confusion may come and go; periods of great confusion are sometimes followed by comparative lucidity.

In other cases, the environment and the behavior of others may affect the relative level of decisionmaking competence. For example, side effects of medications often impair competence, but a change of medication may reduce those effects. Behavior of others may create stresses for a person that diminish decisionmaking capacities, but that behavior can often be altered, or the situations in which it occurs can be avoided. Further, cognitive functioning can sometimes be enhanced by familiar surroundings and diminished by unfamiliar ones. A person may be competent to make a decision about whether to have an elective surgical procedure if the choice is presented in the familiar surroundings of home by someone known and trusted, but maybe incompetent to make that same choice in what is found to be the intimidating, confusing, and unfamiliar environment of a hospital.

Factors such as these mean that even for a given decision, a person's competence may vary over time, and so be intermittent. The values that support the right of the competent person to participate in health care decisions also require that caretakers utilize periods of lucidity when they occur. Sometimes the emergency nature of the situation will not permit this, but it is no doubt possible to involve intermittently competent persons in decisionmaking substantially more than is done at present.

Sometimes, with opportune timing or other appropriate measures (such as medications), the intermittently competent person may be able to be involved in decisionmaking at a time when he or she is clearly competent. Often, however, the person either consistently remains in, or can only be brought to, a state of borderline competence for the decision at hand. These borderline cases of questionable competence require more careful determination. They also illustrate the need for greater sophistication on the part of medical care providers and others about physical and mental problems that frequently affect the elderly.

Capacities Needed for Competence

What capacities are necessary for a person competently to decide about such matters as health care, living arrangements, financial affairs, and so forth? As already noted, the demands of these different decisions will vary, but it is nevertheless possible to generalize some about the necessary abilities. Two may be distinguished: the capacity for communication and understanding, and the capacity for reasoning and deliberation (President's Commission, 1982). Although these capacities are not entirely distinct, significant deficiencies in any of them can result in diminished decisionmaking competence. A third important element of competence is that the individual must have a set of values or conception of the good.

Under communication and understanding are included the various capacities that allow a person to take part in the process of becoming informed on and expressing a choice about a given decision. These include the ability to communicate and the possession of various linguistic, conceptual, and cognitive abilities necessary for an understanding of the particular information relevent to the decision at hand. The relevent cognitive abilities in particular are often impaired by disease processes to which the elderly are especially subject, including most obviously various forms of dementia, but also aphasia due to stroke and, in some cases, reduced intellectual performance associated with depression (pseudodementia). Even where cognitive function is only minimally impaired, ability to express desires and beliefs may be greatly diminished or absent (as in some patients with amyotrophic lateral sclerosis).

Understanding also requires the ability to appreciate the nature and meaning of potential alternatives — what it would be and "feel" like to be in possible future states and to undergo various experiences. In young children this is often prevented by the lack of sufficient life experience. In the case of elderly persons facing diseases with progressive and extremely debilitating deterioration, it is hindered by people's generally limited ability to understand a kind of experience radically different from their own and by the inability of severely impaired individuals to communicate the character of their own experience to others. Major psychological blocks — such as fear, denial, and depression — can also significantly impair the appreciation of information about an unwanted or dreaded alternative. In general, communication and understanding require the capacities to receive, process, and make available for use the information relevant to particular decisions.

Competence also requires capacities for reasoning and deliberation. These include capacities to draw inferences about the consequences of making a certain choice and to compare alternative outcomes based on how they further one's good or promote one's ends. Some capacity to employ rudimentary probabilistic reasoning about uncertain outcomes will commonly be necessary, as well as the capacity to give due consideration to potential future outcomes in a present decision. Reasoning and deliberation obviously make use of both capacities mentioned earlier: understanding the information and applying the decisionmaker's values.

Finally, a competent decisionmaker also requires a set of values or conception of what is good that is reasonable consistent and stable. This is needed in order to be able to evaluate particular outcomes as benefits or harms, goods or evils, and to assign different relative weight or importance to them. Often what will be needed is the capacity to decide on the import and relative weight to be accorded different values, since that may not have been fully determined before a particular choice must be made. Competence does not require a fully consistent set of goals, much less a detailed "lifeplan" to cover all contingencies. However, sufficient internal consistency and stability over time in the values relative to a particular decision is needed to yield a decision outcome. Although values change over time and although ambivalence is inevitable in the difficult choices faced by many persons of questionable competence concerning their medical care, living arrangements, and personal affairs, sufficient value stability is needed to permit, at the very least, a decision that can be stated and adhered to over the course of its discussion, initiation, and implementation.

Competence as a Threshold Concept, Not a Comparative One

Decisionmaking competence, and the skills and capacities necessary to it, is one of the three components in standard analyses of the requirements for informed consent in health care decisionmaking (Beauchamp and Childress, 1983; Beauchamp and Faden, forthcoming; Katz, 1977; Lidz et al., 1984; Meisel, 1979; President's Commission, 1982). The informed consent doctrine requires the free and informed consent of a competent patient to medical procedures that are to be performed. The idea underlying this doctrine is that of a patient's deciding, in consultation with a physician, what health care, if any, will best serve the patient's aims and needs. If the decision is not voluntary, but instead coerced or manipulated, it will likely serve another's ends or another's views of the patient's good, not the patient's own view, and will in a significant sense originate with another and not the patient. If the appropriate information is not provided to the individual in the form the patient can understand, that person will not be able to ascertain how available alternatives might serve his or her aims. Finally, if the patient is not competent, either the individual will be unable to decide at all or the decisionmaking process will be seriously flawed.

Sometimes incompetence will be uncontroversially complete, as with patients who are in a persistent vegetative state or who are in a very advanced state of dementia, unable to communicated coherently at all. Often, however, defects in the capacities and skills noted above as necessary to competence will be partial and a matter of degrees, just as whether a patient's decision is voluntary or involuntary, informed or uninformed, is also often a matter of degree. Does this mean that competence itself should be thought of and said to be more or less competent to perform many tasks, not just decisionmaking. Nevertheless, because of the role competence determinations play in health care generally, and in the legal process in particular, it is important to resist the notion that persons can be determined to be more or less competent, or competent to some degree. The difficulty with taking literally the notion that competence is a matter of degree can be seen clearly by looking at the function of the competence determination within the practice of informed consent for health care, or within other areas of the law in which it plays a role, such as conservatorship or guardianship for financial affairs.

That function is, first and foremost, to sort persons into two classes: 1) those whose voluntary decisions (about their health care, financial affairs, and so on) must be respected by others and accepted as binding, and 2) those whose decisions, even if uncoerced, will be set aside and for whom others will be designated as surrogate decisionmakers. The function of the competence determination, then, is to make an "all or nothing" classification of persons with regard to their competence to make particular decisions, not to make "matter of degree" findings about their decisionmaking capacities and skills. Persons are judged, both in the law and more informally in health care settings, to be either competent or incompetent to make a particular decision — even though the underlying capacities and skill forming the basis of that judgment are possessed in different degrees. Competence, then, is in this sense a threshold concept, not a comparative one (Wikler, 1983).

The foregoing makes clear that the crucial question in the competence determination is how defective an individual's capacities and skills to make a particular decision must be for the individual to be found incompetent to make that decision, so that a surrogate decisionmaker becomes necessary. In keeping with the primary objectives of this paper, the analysis of that question focuses on medical decisions. Here the familiar doctrine of informed consent provides considerable guidance.

The central purpose of assessing competence is to determine whether a patient may assert his or her right to decide to accept or refuse a particular medical procedure, or whether that right shall be transferred to a surrogate. We must therefore ask what values are at stake in whether people are allowed to make such decisions for themselves. The informed consent doctrine assigns the decisionmaking right to patients themselves; but what fundamental values are served by the practice of informed consent? In the literature dealing with informed consent, many different answers — and ways of formulating answers — to that question have been proposed, but we believe the most important values at stake are: 1) promoting and protecting the patient's well-being, and 2) respecting the patient's self-determination. It is in examining the effect on these two values that the answer to the proper standard of decisionmaking competence will be found.

Standards of Competence: Underlying Values

Promotion of Individual Well-Being

There is a long tradition in medicine that the physician's first and most important commitment should be to serve the well-being of the patient. The more recent doctrine of informed consent is consistent with that tradition, if it is assumed that, at least in general, competent individuals are better judges of their own good than others are. The doctrine recognizes that while the physician commonly brings to the physician-patient encounter medical training that the patient lacks, the patient brings knowledge that the physician lacks: knowledge of particular subjective aims and values that are likely to be affected by whatever decision is made.

As medicine's arsenal of possible interventions has dramatically expanded in recent decades, alternative treatments (and the alternative of no treatment) now routinely promise different mixes of benefits and risks to the patient. Moreover, since health is only one value among many, and is assigned different importance by different persons, there is commonly no one single intervention for a particular condition that is best for everyone. Which, if any, intervention best serves a particular patient's well-being will depend in part on that patient's aims and values. Health care decisionmaking thus usually ought to be a joint undertaking between physician and patient, since each brings knowledge and experience that the other lacks, yet that is necessary for decisions that will best serve the patient's well-being.

In the exercise of their right to give informed consent, then, patients often decide in ways that they believe will best promote their own well-being as they conceive it. However, as is well known, and as physicians are frequently quick to point out, the complexity of many treatment decisions — together with the stresses of illness with its attendent fear, anxiety, dependency, and regression, not to mention the physical effects of illness itself — means that a patient's ordinary decisionmaking abilities are often significantly diminished. Thus a patient's treatment choices may fail to serve his or her good or well-being, even as that person conceives it. Although one important value requiring patient participation in their own health care decisionmaking is the promotion of patient well-being, that same value sometimes also requires persons to be protected from the harmful consequences to them of their own choices.

Respect of Individual Self-Determination

The other principal value underlying the informed consent doctrine is respect for a patient's self-determination, understood here as a person's interest in making important decisions about his or her own life. Although often conceived in the law under the right of privacy, the leading legal decisions in the informed consent tradition appeal fundamentally to the right of individual self-determination. No attempt will be made here to analyze the complex of ideas giving context to the concept of individual self-determination, nor of the various values that support its importance. But it is essential to underline that many persons commonly want to make important decisions about their life for themselves, and that desire is in part independent of whether they believe that they are always in a position to make the best choice. Even when we believe that others may be able to decide for us better than we ourselves can, we sometimes prefer to decide for ourselves so as to be in charge of and responsible for our lives.

The interest in self-determination should not be overstated, however. People often wish to make such decisions for themselves simply because they believe that, at least in most cases, they are in a better position to decide what is best for themselves than others are. Thus, when a particular case others are demonstrably in a better position to decide for us than we ourselves are, a part, but not all, of our interest in deciding for ourselves is absent.

Conflict Between the Values of Self-Determination and Well-Being

Because people's interest in making important decisions for themselves is not based soley on their concern for their own well-being, these two values of patient well-being and self-determination can sometimes conflict. Some people appear to decide in ways that are contrary to their own best interests or well-being, even as determined by their own settled conception of their good, and others may be unable to convince them of the mistake. In other cases, others may know little of a person's own settled values, and the person may simply be deciding in a manner sharply in conflict with how most reasonable persons would decide. However, it may be difficult or even impossible to determine whether this conflict is simply the result of a difference in values between this individual and most reasonable persons (for example, a difference in the weights assigned to various goods), or whether it results from some failure of the patient to assess correctly what will best serve his or her own interests or good.

In the conflict between the values or self-determination and patient well-being, a tradeoff between avoiding two kinds of errors should be sought. The first error is that of failing to protect a person from the harmful consequences of his or her decision when the decision is the result of serious defects in the capacity to decide. The second error is failing to permit someone to make a decision and turning the decision over to another when the patient is able to make the decision him- or herself. With a stricter or higher standard for competence, more people will be found incompetent, and the first error will be minimized at the cost of increasing the second sort of error. With a looser or more minimal standard for competence, fewer persons will be found incompetent, and the second sort of error is more likely to be minimized at the cost of increasing the first.

Evidence regarding a person's competence to make a particular decision is often uncertain, incomplete, and conflicting. Thus no conceivable set of procedures and standards for judging competence could guarantee the elimination of all error. Instead, the challenge is to strike the appropriate balance and thereby minimize the incidence of either of the errors noted above. No set of procedures will guarantee that all and only the incompetent are judged to be incompetent.

But procedures and standards for competence are not merely inevitably imperfect. They are inevitably controversial as well. In the determination of competence, there is disagreement not only about which procedures will minimize errors, but also about the proper standard that the procedures should be designed to approximate. The core of the controversy derives from the different values that different persons assign to protecting individuals' well-being as against respecting their self-determination. We believe there is no uniquely "correct" answer t the relative weight that should be assigned to these two values, and in any event it is simple a fact that different persons do assign them different weight.

Deciding on Standards of Competence

Focusing only on the two values of patient well-being and self-determination is an oversimplification. Because other values are at stake, room for controversy about the proper standard of competence increases. For example, also important to the appropriate standard of competence is the value of maintaining public confidence in the integrity of the medical profession, so as to protect and foster the trust necessary to physician-patient relationships that function well.

The standard of competence, then, cannot be discovered. There is no reason to believe that there is one and only one optimal tradeoff to be struck between the competing values of well-being and self-determination, nor, hence, any one uniquely correct level of capacity at which to set the threshold of competence — even for a particular decision under specified circumstances. In this sense, setting a standard for competence is a value choice, not a scientific or factual matter. Nevertheless, the choice need not be and should not be arbitrary. Instead, it should be grounded in 1) a reflective appreciation of the values in question, 2) a clear understanding of the goals that the determination of competence is to serve, and 3) an accurate prediction of the practical consequences of setting the threshold at this level rather than elsewhere.

People may disagree on exactly where the threshold should be set not only because they assign different weights to values of self-determination and well-being, but also because they make different estimates of the probability that others will err in trying to promote a person's interests. Unanimous agreement on an optimal standard is not necessary, however, for workable social arrangements for determining competence, any more than it is for determining who may vote or who may drive an automobile.

Different Standards of Competence

A number of different standards of competence have been identified and supported in the literature, though statutory and case law provide little help in articulating precise standards. It is not feasible to discuss here all the alternatives that have been proposed. Instead, the range of alternatives will be delineated and the difficulties of the main standards will be examined.

No single standard is adequate for all medical treatment decisions, much less also for decisions about living arrangements, financial affairs, participation in research, and so forth. It was argued above that a standard of competence must set a balance between the two principal values at stake in health care decisionmaking: promoting and protecting the patient's well-being while respecting the patient's self-determination.

An example of a minimal standard of competence is that the patient merely be able to express a preference. This standard respects every expressed choice of a patient, and so is not in fact a criterion of competent choice at all. It entirely disregards whether defects or mistakes are present in the reasoning process leading to the choice, whether the choice is in accord with the patient's conception of his or her good, and whether the choice would be harmful to the patient. It thus fails to provide any protection for patient well-being, and it is insensitive to the way the value of self-determination itself varies with differences in people's capacities to choose in accordance with their conceptions of their own good.

At the other extreme are standards that look to the content or outcome of the decision — for example, the standard that the choice be a reasonable one, or be what other reasonable or rational persons would choose. On this view, failure of the patient's choice to match some such allegedly objective standard of choice entails that it is an incompetent choice. Such a standard maximally protects patient well-being — according to the standard's conception of well-being — but fails adequately to respect patient self-determination.

At bottom, a person's interest in self-determination is his or her interest in defining, revising over time, and pursuing his or her own particular conception of the good life. There are serious risks associated with any purportedly objective standard for the correct decision — the standard may ignore the patient's own distinctive conception of the good and may involve the substitution of another's conception of what is best for the patient. Moreover, even such a standard's claim to maximally protect a patient's well-being is only as strong as the objective account of a person's well-being on which the standard rests.

The issue is theoretically complex and controversial, but any standard of individual well-being that does not ultimately rest on an individual's own informed preferences is both-problematic in theory and subject to intolerable abuse in practice. Thus, a standard that judges competence by comparing the content of a patient's decision t some objective standard for the correct decision may fail even to protect appropriately a patient's well-being. An adequate standard of competence will focus primarily not on the content of the patient's decision but on the process of reasoning that leads up to that decision.

While an adequate competence evaluation and standard focuses on the patient's understanding and reasoning, rather than upon the particular decision that issues from them, the key issue remains what level of reasoning is required for the patient to be competent. In other words, how well must the patient understand and reason to be competent? How much can understanding be limited or reasoning be defective and still be compatible with competence? It is important to emphasize another question faced by those evaluating competence. How certain must those persons evaluating competence be about how well the patient has understood and reasoned in coming to a decision? The last question is important because it is common in cases of marginal or questionable competence for there to be a significant degree of uncertainty about the patient's decisionmaking process that can never be eliminated.

Relation of the Standard of Competence to Expected Harms and Benefits

Because the competence evaluation requires setting a balance between the two values of respecting patients' right to decide for themselves and protecting them from the harmful consequences of their own choices, it should be clear that no single standard of competence — no single answer to the questions above — can be adequate. That is simply because the degree of expected harm from choices made at a given level of understanding and reasoning can vary from virtually none to the most serious, including major disability or death.

There is an important implication of this view that the standard of competence ought to vary with the expected harms or benefits to the patient of acting in accordance with a choice — namely, that just because a patient is competent to consent to a treatment, it does not follow that the patient is competent to refuse it, and vice versa. For example, consent to a low-risk life-saving procedure by an otherwise healthly individual should require a minimal level of competence but refusal of that same procedure by such an individual should require the highest level of competence.

Because the appropriate level of competence properly required for a particular decision must be adjusted to the consequences of acting on that decision, no single standard of decisionmaking competence is adequate. Instead, the level of competence appropriately required for decisionmaking varies along a full range from low/minimal to high/maximal. Table 2-1 illustrates this variation.

Table 2-1. — Decisionmaking Competence and Patient Well-Being

Presumed net balance of expected benefits and risks of patient choice in comparison with other alternatives.	Level of decision-making competence required.	Grounds for believing patient's choice best promotes/protects own well-being.
Net balance substantially better than for possible alternatives.	Low/minimal	Principally the benefit/risk assessment made by others.
Net balance of roughly comparable to that of other alternatives.	Moderate/ median	Roughly equally from the benefit/risk assessment made by others and from the patient's decision that the chose alternative best fit patient's conception of own good.
Net balance substantially worse than for another alternative or alternatives	High/ maximal	Principally from patient's decision that the chosen alternative best fits own conception of own good.

The presumed net balance of expected benefits and risks of patient choice in comparison with other alternatives refers to the physician's assessment of the expected effects in achieving the goals of prolonging life, preventing injury and disability, and relieving suffering from a particular treatment option as against its risks of harm. The table indicates that the relevant comparison is with other available alternatives, and the degree to which the net benefit/risk balance of the alternative chosen is better or worse than that for other treatment options. It should be noted that a choice might properly require only low/minimal competence, although its expected risks exceeded its expected benefits, because all other available alternatives had substantially worse expected risk/benefit ratios.

Table 2-1 also indicated, for each level of competence, the grounds for believing that a patient's own choice best promotes his or her well-being. This brings out an important point. For all patient choices, other people responsible for deciding whether those choices should be respected should have grounds for believing that the choice, if it is to be honored, is reasonable in accord with the patient's good and does reasonably protect or promote the patient's well-being (though the choice need not, of course, maximize the patient's interests). When the patient's level of decisionmaking competence is only at the low/minimal level, the grounds derive only minimally from the fact that the patient has chosed the option in question; they principally stem from others' positive assessment of the choice's expected effects for life and health.

At the other extreme, when the expected effects of the patient's choice for life and health appear to be substantially worse than available alternatives, the requirement of a high/maximal level of competence provides grounds for relying on the patient's decision as itself establishing that the choice best fits the patient's good (his or her own particular aims and ends). That highest level of competence is required to rebut the presumption that if the choice seems not best to promote life and health then that choice is not in fact reasonably related to the patient's interests.

When the expected effects for life and health of the patient's choice are approximately comparable to those of alternatives, a moderate/median level of competence is sufficient to provide reasonable grounds that the choice promotes the patient's good and that his or her well-being is adequately protected. It is also reasonable to assume that as the level of competence increases (from minimal to maximal), the value or importance of respecting the patient's self-determination increases as well, since a part of the value of self-determination rests on the assumption that persons will secure their good when they choose for themselves. As competence increases, the likelihood of this happening increases.

Thus according to the concept of competence endorsed here, a particular individual's decisionmaking capacity at a given time may be sufficient for making a decision to refuse a diagnostic procedure when forgoing the procedure does not carry a significant risk, although it would not necessarily be sufficient for refusing a surgical procedure that would correct a life-threatening condition. The greater the risk — where risk is a function of the severity of the expected harm and the probability of its occurrence — the greater the level of communication, understanding, and reasoning skills required for competence to make that decision. It is not always true, however, that if a person is competent to make one decision, then he or she is competent to make another decision so long as it involves equal risk. Even if this risk is the same, one decision may be more complex, and hence require a higher level of capacity for understanding options and reasoning about consequences.

Relation of Refusal of Treatment to Determination of Incompetence

A common criticism of the way physicians actually practice is that patients' competence is rarely questioned until they refuse to consent to a physician's recommendation for treatment. It is no doubt true that patients' competence when they accept physicians' treatment recommendations should be questioned more often than it now is, because consent without understanding provides little basis for believing the choice is best for the patient, and because the physician's judgment about what is medically best is fallible. Nevertheless, treatment refusal does reasonably raise the question of a patient's competence in a way that acceptance of recommended treatment does not. It is a reasonable assumption that physicians' treatment recommendations are more often than not in the interests of their patients. Consequently, it is a reasonable presumption — though rebuttable in any particular instance — that a treatment refusal is contrary to the patient's interest. Exploration of the reasons for the patient's response, including determination of whether the decision was a competent one, are appropriate — though reassessment of the recommendation is often appropriate as well.

It is essential to distinguish here, however, between grounds for calling a patient's competence into question and grounds for a finding of incompetence. Treatment refusal does reasonable serve to trigger a competence evaluation. On the other hand, a disagreement with the physician's recommendation or refusal of a treatment recommendation is no basis whatsoever for a finding of incompetence. This conclusion follows from the premise noted earlier that the competence evaluation, as well as evidence in support of a finding of incompetence, should address the process of understanding and reasoning of the patient, not the content of his decision.

Another essential distinction is between two quite different types of treatment refusal: a refusal of all the treatment options offered, and refusing the one treatment that the physician believes to be best while accepting an alternative treatment that lies within the range of medically sound options. If there is more than one medically sound treatment option — in the sense that competent medical judgment is divided as to which of two or more treatments would be optimal — then the patient's refusal to accept the option that the physician believes is optimal should not even raise the question of the patient's competence, much less entail a finding of incompetence, at least so long as the option the patient chooses lies within the range of medically sound options.

Contrast with Fixed Minimum Threshold Conception of Competence

Before elaborating the implications of this analysis for operational measurements of competence, it will be useful to contrast it with widely held alternative conception that has been implicitly rejected here. According to this other conception — which may be called the "fixed minimal capacity" view — competence is not decision-relative. The simplest version of this view holds that a person is competent if he or she possesses the relevant decisionmaking capacities at some specified level, regardless of whether the decision to be made is risky or nonrisky, and regardless of whether the information to be understood or the consequences to be reasoned through are simple or complex. This concept of competence might also be called the "minimal threshold status complex," since the idea is that if a person's decisionmaking capacities meet or exceed the specified threshold, then the status of being a competent individual is to be ascribed to that person. According to this view, competence is an attribute of persons dependent solely on the level of decisionmaking capacities they possess (though these may vary, of course, from day to day or even from hour to hour, depending upon the effects of disease, medications, emotional states, and so on).

In contrast, according to the conception of competence espoused here, competence is a relational property. Whether a person is competent to make a given decision depends not only upon that person's own capacities but also upon certain features of the decision — including risk and information requirements. There are at least five points in favor of this approach.

First, a concept that allows a raising or lowering of the standard for decisionmaking capacities depending upon the risks of the decision in question is clearly more consonant with the way people actually make informal competence determinations in areas of judgment in which they have the greatest confidence and in which there is the most consensus. For example, you may decide that your 5-year-old child is competent to choose between a hamburger and a hotdog for lunch, but you would not think the could competent to make a decision about how to invest a large sum of money. This is because the risk in the latter case is greater, and the information required for reasoning about the relevant consequences of the options is much more complex. It is worth emphasizing that incompetence due to developmental immaturity, as in the case of a child, is in many respects quite different from the increasing incompetence due to a degenerative disease such as Alzheimer's. However, these and other cases of incompetence do have in common the relevance of the degree of risk for determining the appropriate level of competence.

Second, the decision-relative concept of competence also receives indirect support from the doctrine of informed consent. The more risky the decision a patient must make, and the more complex the array of possible benefits and burdens, the greater the amount of information that must be provided and the higher the standard of understanding required on the part of the patient. For extremely low-risk procedures, with a clear and substantial benefit and an extremely small probability of significant harm, the information that must be provided to the patient is correspondingly less.

Third, perhaps the most important reason for preferring the decision-relative concept of competence is that it better coheres with our basic legal framework in two distinct respects. First, in its treatment of minors, the law has already tacitly adopted the decision-relative concept and rejected the minimum threshold concept. The courts as well as legislatures now recognize that a child can be competent is not an all-or-nothing status — and that features of the decision itself (including risk) are relevant factors in determining whether the child is competent to make that decision (Gaylin, 1982). This approach is increasingly popular, and is utilized in, for example, "limited conservatorships," where some decisionmaking authority is expressly left with the conservatee.

In addition, the law in this country has in general steadfastly refused to recognize a right to interfere with a competent patient's voluntary choice on purely paternalistic grounds — that is, solely to prevent harms or to secure benefits for the competent patient him- or herself. Instead, the law makes a finding of incompetence a necessary condition for justified paternalism. According to the decision-relative concept of competence, the greater the potential harm to the individual, the higher the standard of competence. From this it follows that a finding of incompetence is more likely in precisely those instances in which the case for paternalism is strongest — cases in which great harm can be easily avoided by taking the decision out of the individual's hands. Thus the concept of competence favored here allows paternalism in situations in which the case for paternalism seems strongest, while at the same time preserving the law's fundamental tenet that in general people may be treated paternalistically only when they are incompetent to make their own decisions.

The fourth reason for preferring the decision-relative concept of competence is that it allows a finding of incompetence for a particular decision to be limited to that decision, and so it is not equivalent to a change in the person's overall status as a decisionmaker. Consequently, the decision-relative concept of competence contains a built-in safeguard to allay the fear that paternalism — even if justified in a particular case considered in isolation — is likely to spill over into other areas, eventually robbing the individual of all sovereignty over his or her own life. Further, any finding of incompetence is likely to evoke strong psychological reactions from some patients because to be labeled as "an incompetent" is to be returned to a childlike status. By making it clear that incompetence is decision-relative and hence may be limited to certain areas, the concept of competence used here can at least minimize the potentially devastating assault on self-esteem that a finding of incompetence represents to some individuals.

Finally, the decision-relative concept of competence has another clear advantage over the minimum threshold concept: It allows a better balance between the competing values of self-determination and well-being that are to be served by a determination of competence. The alternative concept, on its most plausible interpretation, also represents a balancing of these fundamental values, but in a cruder fashion (Brock, 1983). Setting a minimal threshold of decisionmaking capacities represents a choice about the proper balance or tradeoff between respect for self-determination and concern for well-being, but it does so on the basis of an extremely sweeping, unqualified generalization — about the probability that unacceptable levels of harm will occur if individuals are left free to choose — over an indefinitely large number of highly diverse potential decisions.

But as indicated earlier, decisions can vary enormously in their information requirements, in the reasoning ability needed to draw inferences about relevant consequences, and in the magnitude of risk involved. Hence any such sweeping generalization will be very precarious. If the generalization errs in one direction — by underestimating the overall harm that would befall individuals if the threshold for competence were set at one level — then the minimal threshold of decisionmaking capacities will be set so low that many people who are judged competent will make disastrous choices. If the generalization errs in the other direction — by overestimating the harm that would result if the threshold were set at a particular level — then many people will be interfered with for no good reason. Thus, regardless of where the minimal threshold is set, it seems likely that it will provide either too much protection or too little. The decision-relative concept of competence avoids relying upon such crude generalizations about harm and permits a finer balance to be struck between the goods of protecting well-being and respecting self-determination.

Operational Measures in the Medical Setting

The next question to be addressed is whether competence can be measured, and if so how. In medical settings, initial judgments about a patient's competence are commonly made in an informal and commonsense way by physicians, other health care personnel, family members, and others. These judgments are often based on rough estimates of the patient's general mental status and the patient's understanding and reasoning in the decision at hand. It has already been noted that a common factor triggering a competence evaluation is the patient's refusal of the physician's treatment recommendation. When a patient's competence appears questionable or borderline, psychiatric consults are commonly sought, at least when they are available, as they are in many hospital settings. Psychiatric evaluations of a patient's competence commonly include both formal and informal components.

Use of Formal Tests to Determine Competence

In psychiatric literature, practice, and research, a number of different tests have been developed and employed to measure formally a person's general mental status. Some of these — such as the relatively brief Mental Health Status Questionnaire — test for attention, for orientation to time and place, and for memory of simple personal and general information. Others, such as the Face-Hand test, also seek to detect the extent of organic brain damage, if any. These test purport only to provide a very crude measure of mental status. For example, the Mental Health Status Questionnaire differentiates the presence of chronic brain syndrome int only four categories: absent or mild, mild to moderate, moderate to severe, and severe.

Other tests are designed to provide more discriminating measures of a person's general mental status. The Neurobehavioral Mental Status Examination, for example, is designed to assess intellectual functioning in five major ability areas: language, constructions, memory, calculations, and reasoning. A mental status profile is then constructed for a particular patient for these various abilities, and the patient's status can be compared with average scores and, for example, with scores of persons with mild to moderate presenile dementia.

No attempt will be made here to assess the validity and reliability to these tests, which will, of course, vary. Rather. the concern is this. Assuming that some such tests are reasonably reliable and valid measures of general mental status, what role should they play in competence evaluations? Primarily because competence is decision-specific in the sense explained earlier, in borderline cases such tests can usually serve only as a somewhat crude initial screen for the patient's competence. When patients are nontestable due to unconsciousness, or when chronic brain syndrome is obviously severe, this will be a reliable indication that the patient is not competent to give or refuse consent for treatment. However, when brain damage is less debilitating, these tests probably best serve as guides for determining whether further examination of the patient's understanding and reasoning in the specific decision at hand is called for. The process of questioning and discussion with the patient will inevitably be more informal than any standardized test, with the special content being tailored to the decision in question.

Importance of Informal Evaluations of Competence

Even when such screening tests fail to indicated any organic brain damage or general cognitive deficits, there may nevertheless be reason to examine further a patient's competence to make a specific decision. For example, incompetence may sometimes result not from organic brain damage, but from psychological processes — such as severe depression, denial, or anxiety — that prevent a patient from achieving adequate understanding and reasoning in the particular decision at hand. Since the denial may function in a relatively limited area, discussion with the patient about the decision in question will likely be necessary to reveal its presence. These psychological factors provide an additional reason — besides their experience in administering mental status exams and diagnosing and assessing organic brain damage — for psychiatrists to play a part in competence evaluations. Psychiatrists are professionally trained and experienced in the diagnosis of various psychological factors that may have a significant adverse effect in a particular decision. Moreover, they are commonly more skilled than many other health care professionals at ameliorating or removing the impact of such psychological factors on a patient's decisionmaking.

In cases of genuinely questionable competence, general mental status exams will always need to be supplemented by an evaluation of the patient's understanding and reasoning in the specific decision at hand. The general tests may serve as useful guides for defects to look for in the decisionmaking at hand, but the brain damage and general abilities that they measure are often sufficiently variable and uncertain in their effects in a particular instance of decisionmaking to require more specific evaluation.

Does the necessity for this more specific and informal evaluation of a patient's particular decision mean that competence does not in the end admit of measurement? It is a common criticism of competence evaluations that they are intuitive and lack any theoretical basis because they are based on no single, uniform, and precise measure of competence. And, of course, if they are merely intuitive in this way, they are likely to be particularly susceptible to evaluator bias, prejudice, and discrimination, and to use widely varying standards for competence.

The fact that no one has proposed a single unified scale or numerical measure of competence applicable to every decision and decisionmaker does not indicate, however, that judgments of competence rest on nothing more than intuitive criteria. Instead, the lack of such a scale merely reflects the reality that competence involves too complex a meshing of various capacities and skills of each patient with the demands of a specific decision situation to yield a formal summary. The potential situations are too numerous and the potential arrays of patient decisionmaking abilities and disabilities are too varied. But in any particular case, the various capacities and skills of understanding and reasoning noted above as necessary to competence in decisionmaking can each be measured on a relative scale and reasons can be offered for the importance of specific deficiencies that limit a person's overall competence to make that decision. Thus, although decisions about a patient's competence to make a given decision are complex and not amenable to simple codification by any single measure, they need not be intuitive in the sense of being inchoate, arbitrary, or purely subjective.

Operational Measures in Nonmedical Settings

So far, the analyses both of the concepts of competence and incompetence and of appropriate standards and measurements have focused on the case of medical care decisionmaking. That is a central focus of this paper, and a significant body of literature, both medical and legal, exists on competence for medical treatment decisionmaking. However, there are at least three other broad classes of decisions also of concern in this paper: 1) decisions about participation in research protocols, 2) decisions concerning financial affairs, and 3) decisions about living arrangements.

The conceptual analysis developed thus far, as wll as the account of the manner and extent to which competence can be measured and the argument for a decision-specific and variable standard of competence, hold as well for these other kinds of decisions. Here, too, the objective is to protect persons' well-being — often primarily physical well-being in the case of research participation and living arrangements, financial well-being in the case of financial affairs and other contractural matters — when their own decisionmaking capacities may be deficient and their decisions threaten them with significant harm or loss of benefit, while at the same time respecting their interest in self-determinating in directing their own lives for themselves and according to their own conception of their good.

Who Should Decide About Competence?

It appears that the principal difference between these kinds of decisions and those on medical treatment lies in who should be called upon to make competence determinations, as well as the appropriate procedures for surrogate decisionmaking in the case of incompetence. These issues will be addressed in greater detail later in this paper.

Some difference regarding competence for these other kinds of decisions should be noted here, however. Perhaps the most important is that the persons who may be involved in a competence evaluation in these other types of decisions — investigators in the case of research, family members in the case of financial and living arrangements — are probably in general more likely to be subject to conflicts of interest with the person whose competence is in question than are physicians in the case of medical treatment. Although medicine has a powerful and traditional commitment to serving the patient's interests, the principal commitment of research investigators is to further knowledge, and family members will naturally be concerned with their own interests, which may often be in conflict with the person whose living arrangements or control over financial affairs is in question. Consequently, in such cases a person's disagreement with the recommendations of others provides no grounds for call the individual's competence into question or triggering evaluation of his or her competence. Independent grounds for questioning the person's competence are necessary.

Furthermore, the increased potential for conflicts of interest in these other kinds of decisions argues strongly against reliance on the informal determinations that are common in medical care decisionmaking. Determinations of competence for decisions about financial matters and living arrangements should commonly be judicial ones. The decision to place a patient in a nursing home is not itself simply a medical decision — though, of course, medical judgment will be one basic component of the decision. Consequently, more formal safeguards are needed for this type of decision than for medical decisions in general. For the same reasons, competence determinations for research participation should at the very least involve disinterested third parties (such as institutional Review Boards for research involving human subjects). Details of such procedures are explored further in chapter 4.

Varying Standards of Competence

Although the proper standard for decisionmaking competence is still determined by a balance between protecting a person's well-being and respecting his or her self-determination, the particular harms and benefits in prospect from the decisions will, of course, differ with these other kinds of decisions. In the case of research participation, or at least of nontherapeutic research, there will rarely be major benefits secured or harms averted for the subject by agreement to participate, and so there will be little if any place for the minimal standard of competence. Other considerations — such as that noted earlier of maintaining public confidence in the research enterprise — also argue against use of the minimal standard for competence of mere awareness of what is to be done and assent, with its potential both for exploitation of subjects and for giving the appearance of exploitation.

In the case of decisions about financial affairs and living arrangements, the weight that should be given to self-determination would appear to be at least as great, if not often greater, than with medical treatment decisions. Financial matters and living arrangements often have as great an impact on an individual's life, and on control over major aspects of life, as do most medical decisions, with the exception perhaps to forgo life-sustaining treatment. As one writer on guardianship laws and practices has noted:

> It may be difficult to underestimate the psychological impact of depriving an individual of the right to manage his own property as he sees fit. Surrogate management of one's finances has been described as 'the kind of intervention [which] is a basic deprivation of a right cherished in a free society: the right for an individual to self-determination.' For an elderly person struggling to maintain his independence and self-esteem in the face of forced inactivity due to mandatory retirement, the loss of control over assets accumulated during a working lifetime may be a critical blow to the individual's sense of integrity. The right to 'acquire, enjoy, own and dispose of property' has received judicial recognition as a fundamental attribute of citizenship; an essential pre-condition to the realization of other basic civil rights and liberties' (Horstman, 1975).

It is therefore ironic that so much ethical analysis and public attention has focused on medical treatment decisions and so little on "mere" financial or placement decisions.

Moreover, many decisions about the use of an individual's financial resources or where and how to live are more clearly questions of personal preference about which there is no objectively correct answer than are decisions about medical care. Thus, there may be an even stronger case for respecting individual choices in these cases.

Difficulties Raised by Determinations Regarding the Incompetent's Finances

In the case of the financial matters of the elderly, competence is generally not treated in the law as decision-specific in the way that we have argued it should be — at least in medical matters involving persons of borderline, questionable, partial, or intermittent competence. Of course, even in medical matters, perhaps most persons will be either clearly competent (for example, normal adults) or clearly incompetent (for example, unconscious or severely demented patients) to make any treatment decisions.

But in financial matters, there is a factor external to the condition of the patient that make the decision-specific treatment of competence difficult even in cases of borderline competence. That is the common involvement in a person's financial dealings of other persons, often many other persons. It is important that these others be able to know whether they can rely on agreements, undertakings, and contracts with the person in question. Understanding competence as decision-specific in financial matters would sometimes make financial dealings with the person in question unacceptably unpredictable and unreliable. Together with special worries about financial exploitation of marginally competent persons, this consideration must at the least substantially limit the extent to which competence about financial matters should be treated as a decision-specific determination.

At this point, a painful dilemma for individual conduct and public policy becomes apparent. On one hand, the need to avoid disruption of the legitimate expectations of others who are affected through contractual relationships argues for global, rather than decision-specific, determinations of incompetence with respect to financial decisions. On the other hand, global determinations of incompetence for individuals who are in fact competent to make some financial decisions can lead to "total takeovers" of their lives by others — not only violating their right of self-determination, but also in some cases precipitating a decline in physical and psychological well-being. The fundamental ethical issue here is one of distributive justice: To what extent may the right to make decisions that a person is competent to make be compromised by considerations of the rights and interests of others (Wikler, 1983)? Issues of distributive justice are addressed in more detail in chapter 4.

Despite these qualifications, essentially the same conceptual framework developed here for medical treatment decisions generally can be applied to these other kinds of decisions. Of course, in the concrete application of that framework, exactly what capacities for understanding and reasoning will be called on, and exactly how particular conditions of the person may affect those capacities, will vary depending on the kind of decision in question. Similarly, the institutional procedures that are feasible and appropriate for surrogate decisionmaking will vary as well.

Summary of Conclusions Concerning Competence

As this paper is on decisionmaking for elderly people who are incompetent or of questionable competence, it is necessary to clarify at the outset the nature of the judgment that an individual is incompetent. Since so much will hang upon whether a person is determined to be competent or incompetent, this task of clarification is of the greatest importance. The major conclusions established in this regard are the following:

Competence is competence for some task, competence to do something. More specifically, the concern is with competence to make a decision (e.g., regarding health care, living arrangements, financial affairs, and so on).

The necessary decisionmaking capacities include:

- communication and understanding,
- relatively stable values or a conception of the good life, and
- reasoning and deliberation.

Appropriate standards for competence will focus primarily on the process of reasoning, not on the decision itself.

The point of a competence determination is to sort people into two classes: those whose decisions must be respected, and those whose decisions will be set aside and for whom others will be designated as surrogate decisionmakers. Competence, then, is not a matter of degree — a person either is, or is not, competent to make a particular decision. Thus competence is a threshold concept, not a comparative one.

Setting the proper level of decisionmaking competence involves balancing two important values: protecting and promoting the individual's well-being, and respecting the individual's self-determination. In balancing these two values, it is important to avoid two types of errors: 1) failing to protect the interests of an incompetent person, and 2) failing to respect the self-determination of a competent person. The looser the standard for competence, the more common will be the first type of error; the stricter the standard for competence, the more common will be the second type of error. Deciding how to set the standard for competence — so that it avoids both types of errors — is not a scientific or factual matter, but rather a value choice (though not an arbitrary one).

No single standard for competence is adequate for all decisions. The standard depends in large part on the risk involved, and varies along a range from low/minimal to high/maximal. The more serious the expected harm to the patient from acting on a choice, the higher should be the standard of decisionmaking capacity, and the greater should be the certainty that the standard is satisfied. In particular, the following should be noted:

- If the net balance of the expected benefits and risks from the patient's choice is substantially better than for possible alternatives, then the level of decisionmaking capacity required is low/minimal.
- If the net balance of the expected benefits and risks from the patient's choice is roughly comparable to that of other alternatives, then the level of decisionmaking capacity required is moderate/median.
- If the net balance of the expected benefits and risks from the patient's choice is substantially worse than for other alternatives, then the level of decisionmaking capacity required is high/maximal.

Some treatment refusals may reasonably trigger competence investigations, but refusal of treatment itself is not proof that a patient is incompetent. A patient's rejection of the physician's first choice for treatment should not even trigger an inquiry into the patient's competence if the patient chooses instead a treatment that also falls within the range of medically sound options.

In cases of questionable competence to decide on medical treatment, general mental status exams are not sufficient, and must be supplemented by an evaluation of the patient's understanding and reasoning in the specific decision at hand.

Because of the potential for conflicts of interest, judicial determinations of competence for decisions about financial matters and living arrangements are generally necessary. Competence determinations for research participation must involve disinterested third parties (such as Institutional Review Boards). Determinations in medical settings may remain somewhat more informal.

CHAPTER 3: AN ETHICAL FRAMEWORK

Once it has been determined that an individual is incompetent to make all or some decisions of a given type, a number of perplexing ethical issues arise. The most obvious questions that must be answered are: Who should decide for the incompetent? And according to what principles should decisions be made? The issues are, however, considerably more complex than this. What is needed is a systematic ethical framework capable of distinguishing and answering not only these but other equally important questions as well. It is useful to think of such a framework as a theory of surrogate decisionmaking — whereby a "theory" is meant a coherent set of principles related to one another in a systematic way.

It is essential to distinguish among different types of principles that together constitute the needed theory. The most fundamental of these are the following:

Ethical Value Principles - principles that specify the basic ethical values that are to be served in dealing with incompetent individuals. These values are primarily: respect for individual self-determination, concern for individual well-being, and distributive justice. Of course, other important values, such as community and charity, also are relevant.

Guidance Principles - principles that provide substantive direction as to how decisions are to be made. These include:

- best interest - acting so as to promote maximally the good of the individual;
- substituted judgment - acting according to what the individual, if competent, would choose; and

- advance directive - implementing an advance directive, such as a "living will" or durable power of attorney, that the patient executed while competent.

Authority Principles - principles that specify who is to make decisions concerning incompetent individuals.

Intervention Principles - principles specifying the conditions under which the courts, representatives of government protective agencies, or others in various institutional roles are to intervene so as to take decisions out of the hands of those whose presumptive authority to decide was acknowledged in the Authority Principles. An example might be a principle stating that the court may remove an individual from the care of his or her spouse and appoint a public guardian if it is believed that the spouse is clearly acting contrary to the individual's important interests.

Failure to distinguish these four types of principles can lead not only to conceptual confusion but also to grave practical errors. For example, there are many cases in which the Best Interest Principle is appropriate to guide a surrogate's decision, but this same principle would be wholly inappropriate if taken as specifying the conditions under which others may rightfully intervene and wrest decisionmaking power from the surrogate. Although a surrogate ought to try to act in the incompetent's best interest, requiring success in this effort is too stringent a requirement. This holds true in general, not just for decisions concerning elderly incompetents. Although we think that parents ought primarily to be guided by what is best for their children, we recognize that it would be intolerably intrusive to intervene to transfer custody whenever doing so would result in a net increase of benefit to the child. The fact that another, wealthier couple could provide a better education is not a sufficient reason for removing a child from his or her natural parents, even if this could be done without psychological harm to the child.

To think of the task as that of constructing a theory of surrogate decisionmaking is helpful because it enables us to sort out various issues that arise at different levels. However, a fully adequate theory — complete with crisply formulated principles to cover every contingency — must be understood as a regulative ideal, not as a realistic expectation. Any actual set of social arrangements for dealing with these complex issues will necessarily involve compromises, and any set of principles will leave some questions unanswered.

Even a theory that is fully internally consistent and that provides answers in principle to all crucial questions would not be enough unless it satisfies what may be called feasibility constraints. For example, a theory that makes unrealistic moral demands on people by ignoring human psychology and the financial and institutional incentives under which individuals operate is of little practical significance. On the other hand, a theory should enable criticism of the existing institutional framework within which decisions are now made. Throughout the remainder of this paper, every effort will be made to tread a narrow line between utopian moral exhortations that ignore the inertia of existing practices on the one had, and a premature pessimism concerning the possibility of changing defective arrangements on the other.

ETHICAL VALUE PRINCIPLES

The dominant tendency, both in recent legal doctrine and in the bioethics literature, has been to view the rights of incompetent individuals as an extension of the rights of competent individuals, through arrangements by which these rights are exercised for the incompetent by others. Although many bioethicists are sharply critical of attempts to apply this approach to those incompetent individuals who were never competent, it is generally agreed that the appropriate starting point for a theory of decisionmaking for incompetents is the rights of competent individuals. And here, as in the analysis of competence in chapter 2, decisions concerning medical care will be the point of departure and primary focus.

The Scope of the Competent's Patient's Right to Refuse Treatment

There is now broad agreement in public opinion, in the writings of bioethics, and in the law that a competent patient has the right to refuse medical care, even life-sustaining medical care (Beauchamp and Childress, 1983; Beauchamp and Faden, forthcoming; Buchanan, 1983; Lidz, et al., 1984; President's Commission, 1982, 1983a). Although the majority of cases in which courts have affirmed this right involved situations in which most would agree that prolonging life was of dubious net benefit to the patient, several influential rulings have held that a competent patient has the right to refuse treatment that most reasonable people would accept (In re Brooks Estate, 1965; In re Yetter, 1973). What is acknowledged in principle, however, is not always respected in practice. Several recent studies indicate that many physicians continue to behave paternalistically, even while professing to respect the patient's right of self-determination (Angell, 1984; Bedell and Delbanco, 1984; Evans and Brody, 1985, Lidz, et al., 1984).

The ethical foundation of the competent person's right to refuse treatment, as has already been suggested in chapter 2, is twofold. First, self-determination is of great instrumental value for a competent individual — the assumption being that a competent person's own choices, at least under conditions of consent, are more likely to promote whatever particular interests that person has better than are choices made by others. Second, self-determination is said to be something of considerable value, independently of whether it does in fact enable an individual to promote other interests.

The ethical basis of the right of self-determination for competent individuals acknowledges no distinction between the refusal of life-sustaining treatment and the refusal of life-sustaining care, including nutritional support (whether it be ordinary feeding or "artificial" nutrition by nasogastric tube, intravenous tube, or gastronomy). From the standpoint of respecting individual self-determination and promoting individual well-being, extending a competent patient's life by forced feeding is no more acceptable than forcibly maintaining that individual on a respirator. In some cases, a death hastened by dehydration and malnutrition may in fact even be less painful that the discomfort and terror of asphyxiation that sometimes follow removal of a respirator (Lynn and Childress, 1983). In either case, appropriate sedation can avoid unnecessary pain once the decision to withhold support has been made (President's Commission, 1983a).

The fact that feeding is one of the first and most familiar forms of caring experienced by human beings endows it with considerable symbolic significance, at least for some people. This symbolic significance — when combined with the tendency of those who characterize termination of nutritional support as "starving" the patient — has served to obscure the fact that there is no ethical distinction *per se* between removing a respirator and removing a feeding tube or even ceasing ordinary feeding. The term "starvation" functions only as prejudicial rhetoric, because of its associations with cases outside of the medical setting in which deliberately withholding food from an individual involves malicious or callous neglect. But the immorality of these other, quite different cases is irrelevant to the moral status of withholding nutritional support when this is freely chosen by a competent and informed patient who does so only to bring a quicker end to what he or she believes to be futile suffering.

The competent patient, then, has the moral right to refuse nutritional support, whether by ordinary feeding or by artificial means. Since such support might more aptly be called care rather than treatment, it may be more useful to say that the competent individual has the right to refuse medical treatment and care. At least two important recent court rulings have clearly affirmed a legal right to refuse artificial feeding as well as respirator support (In re Conroy, 1985; Barber v. Superior Court, 1983). The reasoning the courts used to justify this conclusion also tends to support the broader conclusions that there is a legal right to refuse "natural" feeding as well, though the courts themselves have not yet explicitly drawn this implication.

Although the factors that justify withholding "artificial" feeding in principle justify withholding "natural" (spoon) feeding under the same circumstances, it can be argued that social policy and the law should treat the two differently. One important reason for this is that the circumstances will rarely be the same. The vast majority of patients who can be fed without artificial means are either able to make their own decisions about whether to accept food or are not so ill that a surrogate could properly conclude that continued feeding would be of no benefit to them. Withholding "natural" feeding thus has a greater potential for error and abuse than the withholding of "artificial" feeding. Consequently, it may be prudent to require stricter protections against decisions to forgo "natural" feeding for incompetent patients, to minimize the risk of unsound decisions.

Limitations on the Competence Person's Right to Refuse Treatment

The most obvious and uncontroversial limitation on the right of the competent person, recognized both in the law and in bioethics, is that it does not include the right to subject others to significant health risks. A person, for instance, may not refuse treatment for a highly communicable serious disease.

Another important limitation is that the right to refuse treatment and care is not a right to receive whatever services the patient demands. Whether or not there is a general moral right to health care is a much disputed question (President's Commission, 1983-Access Appendices; Buchanan, 1984; Daniels, 1985). It is clear, however, that at present in the United States there is no recognized Constitutional or general statutory legal right to health care (President's Commission, 1983-Access Report). Even if there is a moral basis for the legal recognition of such a right, the right in question would be distinct from the right to refuse treatment and care. The former would be a positive right, a right to have medical services rendered; the latter is a negative right, a right not to have medical treatment or care provided to an individual without his or her consent.

There are, of course, special ethical and legal positive rights, including rights to specific medical treatments, that arise in the contractual or quasi-contractual relationships between a particular physician and illustrates the importance of distinguishing between special Bouvia, was a young woman paralyzed with cerebral palsy (Bouvia v. County of Riverside, 1984). She voluntarily admitted herself to a psychiatric hospital inpatient ward, and then refused nourishment with the announced intention of ending a life of disability that she professed was intolerable. But not only did she refuse life-sustaining nutrition — which she had the right to do — she also demanded that the hospital continue to provide her with a place to stay and with palliative and hygienic care during the period of her death by malnutrition.

In the absence of a general right to health care, her basis for this would have to be a special right generated by the contractual relationship between her and her physician. However, no evidence of any explicit agreement of this sort was produced. Further since withholding nutritional support from competent patients who are not terminally ill and not in intractable pain is not standard practice, it would be implausible to maintain that the patient had a special right to receive the kind of care she requested by virtue of an implicit contractual agreement. In the absence of a special or general right, then, the physician was justified in refusing to provide palliative and hygienic care without providing sustenance.

It must be emphasized that it does not follow that the patient had no right to refuse nutritional support and that forcible feeding was permissible. Instead, the physician could acknowledge the right to refuse treatment by transferring the patient to another physician, or to family or friends who would be willing to withhold nutritional support while providing palliative and hygienic care. As the Bouvia case clarifies, the proper justification for a physician's refusal to withhold nutritional support is not that the right of self-determination does not include the right to refuse food, but rather the right of self-determination is not a right to force health providers to provide whatever mix of care and withholding of care a patient demands, regardless of the moral scruples of the providers and prevailing standards of care.

For the same reasons, the right of self-determination in medical treatment and care decisions (being a negative right, a right to be free from interference or invasion) does not include the right to be killed. Whether or not taking positive actions, such as administering a lethal injection at the voluntary and informed request of a competent person, is ever ethically or legally permissible is a different question altogether. At present the law in this country prohibits voluntary active euthanasia, thus limiting the patient's legal right of self-determination to a negative right to refuse life-sustaining treatment. However, at least one Western European country, the Netherlands, has now legalized active voluntary euthanasia under certain highly circumscribed conditions.

To summarize, the competent individual's right of self-determination with respect to medical decisions is a right to refuse all forms of medical treatment and care, including nutritional support by ordinary or artificial means, except when refusal imposes significant health risks on others. It is not a right to demand services, nor a right to be killed.

As will become apparent, a proper understanding of the competent individual's right to decide provides an important — albeit far from complete — basis for an ethically and legally sound theory of decisionmaking for those who are incompetent. The strategy here will be first to examine the issue of what principles ought to direct decisionmaking for incompetent elderly people (Guidance Principles), and then address the question of where decisionmaking authority ought to be located (Authority Principles). Only when the scope and limitations of the various Guidance Principles is appreciated will it be possible to demarcate accurately the proper division of decisionmaking responsibility as well as the sharing of decisionmaking authority.

GUIDANCE PRINCIPLES

Three distinct Guidance Principles have been proposed and widely discussed.

The Best Interest Principle states that a surrogate is to choose what will best serve the patient's interests. The qualifier "best" indicates two important factors: Some interests are more important than others in that they make a larger contribution to the patient's good and a particular decision may advance some of the patient's interests while frustrating others. Thus, according to the Best Interest Principle, the surrogate must try to determine the net benefit to the patient of each option, after assigning weights reflecting the relative importance of various interests affected when subtracting the "costs" from the "benefits" for each option.

In contrast, the Substituted Judgment Principle states that a surrogate is to choose as the patient would choose if the patient were competent and aware both of the medical options and of the facts about his or her condition, including the fact that he or she is incompetent. Thus a surrogate who must decide whether antibiotics should be given to an unconscious man with terminal cancer might consider the following as a test of the

Substituted Judgment Principle: "If the patient miraculously were to awaken from this coma for a few moments, knowing that he would soon lapse back into it, would he choose to have antibiotics administered?"

A third Guidance Principle may be called the Advance Directive Principle: It states that where a clear and bona fide advance directive is available, it is to be followed. There are two broad types of advance directives: instructional and proxy (President's Commission, 1983a). An instructional advance directive is an instrument whereby the patient, when competent, specifies, perhaps only in rather general terms, which types of treatment he or she wishes to have or, more commonly, not have, under certain circumstances, should the person become incompetent. So-called living wills are the most familiar instances of instructional advance directives. In a proxy advance directive, a competent individual designates some other individual or individuals to serve as the surrogate should the person become incompetent. These two types of advance directive may be combined: An individual might designate his or her spouse as proxy but include instructions that place limits upon that person's discretion to decide the individual's fate.

A distinctive feature of the Advance Directive Principle is that it — unlike the Best Interest and Substituted Judgment Principles — provides an answer not only to the question of how decisions are to be made, but also who is to make them. It locates decisionmaking authority in the formerly competent individual. Thus the Advance Directive Principle offers the simplest extension of the competent patient's right of self-determination to the problem of decisionmaking for incompetents. It is at best a partial solution, however, for three reasons. First, some incompetent individuals (such as those severely retarded from birth) never were competent, and hence never were qualified to issue advance directives. Second, at present the vast majority of those who are or will become incompetent have issued no advance directives (President's Commission, 1982;

MHCD; Anderson, et al., 1984). Third, even where advance directives exist, it is still necessary to locate authority and responsibility for interpreting and implementing them.

Conflicts Among Guidance Principles

Which Guidance Principle is followed can make a difference — in some cases, the difference between life and death. Acting in the patient's best interest can be incompatible both with choosing what the patient would choose if competent and with following an advance directive, whether it be of the instructional or proxy variety. This is not surprising, since the Best Interest Principle focuses exclusively on the patient's well-being, while both the Substituted Judgment and Advance Directive Principles require that respect for the patient's former choices and values be decisive. As the debate over paternalism shows, concern for well-being and respect for autonomy can be incompatible (Sartorius, 1983). Since competent persons sometimes make choices contrary to their own best interest, both following an advance directive and choosing what the patient would choose if competent can be incompatible with acting in the patient's best interests.

In addition, substituted judgment can yield a decision that is incompatible with following the patient's advance directive. What a person now (at the time of incompetence and illness) would choose were he or she competent may be different from what, at an earlier time before the person was either incompetent or ill, that said he or she wished to be done if incompetence and illness arose.

It might be thought that if an advance directive conflicts with the decision yielded by substituted judgment, then the discrepancy between the two must be the result of either one or both of two circumstances: failure on the part of the patient, when competent, to envision concretely and accurately the circumstances in which the treatment decision must be made, or a change in the individual's values after the advance directive was issued (and before the person became incompetent). Thus it might be assumed that where the two conflict, the surrogate should use substituted judgment and ignore the advance directive — on the grounds that if the patient had not suffered from a lack of imagination or information, or if the patient had anticipated the change in values, the person would have issued a different advance directive.

This amounts to a decision to view advance directives as evidence of what the patient would choose if competent, and robs the Advance Directive Principle of its status as an independent Guidance Principle. On this view, if it is though that the patient's values did not change during the interval between the issuing of the advance directive and the onset of incompetence, and that at the time of issuing the advance directive the patient did accurately envision the later treatment situation, then the advance directive is taken as conclusive evidence of what the patient would (now) choose if competent.

The discrepancy between an advance directive and substituted judgment, however, may have an altogether different source. An individual might issue an advance directive stating that he or she is not to be sustained by dialysis if severely brain-damaged, because of a moral conviction that the resources that would be used to keep the person alive ought to be used for others who are normal or who have less serious mental impairments. Yet if the individual were miraculously to regain competence for a few moments, the person's self-interested motivation might override the moral conviction, and the patient might choose to be given antibiotics and other forms of life support. In such a case, there is a genuine and inescapable conflict between the advance directive and substituted judgment, one that cannot be resolved by saying that the advance directive should be overridden because it was issued without an adequate appreciation of what the future would be like or because the patient's values changed.

Since different results may emerge, depending upon which Guidance Principle is followed, some way of ordering these principles in situations in which more than one could be applied is needed. One appealingly simple rule has been proposed by the recent Presidential Commission on Medical Ethics, and enjoys widespread support: Where a valid (i.e., bona fide) and clear advance directive applies, it is to take precedence over any other Guidance Principle, including best interest and substituted judgment (President's Commission, 1983a).

The Advance Directive Principle

The popularity of giving priority to a clear and bona fide advance directive is not hard to understand. The same strong reasons for affirming the right of the competent patient to accept or reject treatment offered when the person is competent seem to weigh heavily in favor of following an advance directive. Society affirms the right of the competent patient to refuse or accept treatment because self-determination is valued both for its own sake and as something of great instrumental value. A person can exercise self-determination not only by accepting or rejecting treatment that is now offered, but also by making decisions that will influence what is to happen in the future, when the person becomes incompetent.

Consequently, following an advance directive can be viewed as a case of respecting self-determination, even if the individual has no self-determination to respect at the time the advance directive is carried out. Further, although exercising substituted judgment can also be seen as a way of respecting self-determination, the often highly conjectural nature of attempts to ascertain what the patient would want if competent is so subject to abuse and error that the most reliable way to show respect for self-determination is, at least in general, to follow an advance directive where one exists. Those who know the patient best may have a serious conflict of interest that may distort their speculations about what the patient would want if competent.

The Case Against Always Giving Priority to Advance Directives

Objections to a blanket policy of following advance directives — including objections to giving priority to them where doing so conflicts with other Guidance Principles — can be grouped rather roughly under two broad headings: practical problems, and moral objections.

Practical Problems. The most obvious reservation about adhering to an advance directive, especially when doing so will result in the patient's death, is that the directive may not be valid for any of several reasons. Doubts may exist as to whether the person who issued it was competent at that time to make the decision expressed in the advance directive, adequately informed about the situations covered by such directives, or voluntary issuing the directive. In the case of a proxy directives, there is the additional problem that the designated surrogate must also be competent and adequately informed. None of these concerns about validity is unique to advance directives, however. Each has an analog in the conditions for informed consent on the part of a competent patient who must accept or refuse treatment offered when the person is competent. In addition, the instructions about treatment included in an advance directive may be ambiguous, and therefore difficult to interpret.

Without denying the potential seriousness of any of these problems, it is important to emphasize that the institutional, procedural safeguards that are needed to ensure informed consent for competent patients' choices can be adapted for advance directives (President's Commission, 1983a). There is, however, at least one difficulty that is peculiar to advance directives. Although the competent patient need only have adequate information about the actual treatment decision that must be made, the individual formulating an instructional advance directive must draft it so as to cover an indeterminate range of contingencies and will not be able to be informed fully about each in advance.

One salient advantage of proxy over instructional directives is that by designating in advance a surrogate decisionmaker, the individual can avoid the impossible task of attempting to envision all treatment decision situations that might arise should he or she become incompetent. This advantage, however, comes at a price. First, it would be unfortunate, as well as ironic, if an instrument designed to help people determine their fates in accordance with their own distinctive values concerning death and dying became a means for some to evade the question of what those values are or ought to be by simply throwing the responsibility on to a proxy, without adequate discussion and without limiting the authority of the proxy by carefully considered instructions. In other words, proxy advance directives might for some people serve as a means for relinquishing their self-determination and for the denial of death.

Second, although an individual who uses a proxy directive needs to know less about particular choice situations that may arise than someone who employs an instructional advance directive, he or she must know a good deal about the decisionmaking capacities and moral character of the surrogate. In particular, the person must be able to estimate accurately the motivation of the surrogate. There are two sources of error in this regard. The individual may unwittingly designate a proxy who, even at that time, is not primarily concerned either with the patient's best interests or with choosing in accordance with the patient's values. Or, the very process that renders the individual in need of a treatment decision but unable to decide on it may change the surrogate's motivation, by creating or exacerbating a conflict of interest. Financial and emotional slavery to a demented and chronically ill spouse or parent, for example, may erode even the deepest loyalties. Like the problems concerning the validity of advance directives, the worry that the interests of those other than the patient may inappropriately influence treatment decisions are not unique to decisions for incompetent patients. The greater vulnerability of the incompetent patient, however, requires that special legal and institutional safeguards be developed. Any recommendations concerning appropriate safeguards must rest, on a clear appreciation of current practices, which are examined in chapter 4.

Moral objections. More-based moral considerations favor limiting or overriding the authority of advance directives, even in cases where there are no doubts about the validity of the document. It can be argued that an advance directive that clearly runs contrary to the individual's basic interests may sometimes be overridden on paternalistic grounds — because the reasons that support the right to refuse medical care and treatment in the case of a competent patient who is now making a decision have less force in the case of a choice about a decision to be implemented in the distant future under radically altered circumstances. The paternalistic arguments challenge the simplistic assumption that if the competent individual has the right to refuse life-sustaining treatment, then the same choice always ought to be considered binding by others if the individual makes it concerning a future decision situation in an advance directive.

This assumption is flawed because it overlooks several morally significant asymmetries between the contemporaneous choice of a competent individual and the issuance of an advance directive to govern future decisions. First, even if at the time an advance directive was issued, an individual was well informed about the options available should he or she develop a particular disease, therapeutic options and hence prognosis can change between the time the advance directive is issued and the time it is to be implemented. For example, granged the current lack of a cure for Alzheimer's disease, some persons might issue an advance directive stating that if they are diagnosed as having this disease, certain life-sustaining measures (from respirators to antibiotics) are not to be used. However, in the interval between the issurance of such a directive and the point at which the need for such measures arises, unforeseen successes in treatment might develop. Similarly, had advance directives been widely used 10 or 15 years also, some individuals might have requested withholding of some life-sustaining measures should they become afflicted with Hodgkin's disease or testicular cancer — two diseases that previously were regarded as a virtual death sentence but that now are treated with considerable success in some cases.

Requiring that advance directives be reevaluated and reaffirmed or modified periodically (say every 5 years) may reduce the problem, but the sometimes rapid and unpredictable changes in therapeutic options ensure that it will not be eliminated. Another way of coping with this problem would be for legislation concerning advance directives to exclude those that mention specific diseases. Although there is never any guarantee that a competent individual making a decision to refuse treatment that is now being offered will choose on the basis of an adequate understanding of the full range of currently existing therapeutic options and prognostic predictions, the problem is clearly greater in the case of advance directives, and weakens the case for a virtually unlimited right to refuse future treatment.

The second morally relevant difference is that the assumption that a competent person is the best judge of his or her own interests is weaker in the case of a choice about future contingencies under conditions in which those interests may have changed in radical and unforeseen ways it is in the case of a competent individual's contemporaneous choice. What is in an individual's interest — what contributes to his or her well-being — depends in part upon what that individual's capacities are for activity, pleasure, and enjoyment. Competent persons, at least on average and in the long run, are thought to be the best judges of what is conductive to their well-being in part because they are best acquainted with their own capabilities. However, severe illness or trauma of the sort that extinguishes or diminishes an individual's competence to make various decisions often also radically changes the individual's other capacities. For example, the active 40-year-old university professor who relishes enjoyments requiring complex cognitive and social skills may be unable to appreciate adequately the less sophisticated pleasures and enjoyment that would constitute his or her well-being were he or she to suffer serious loss of some higher brain function due to stroke or other illness. The professor may, in fact, confuse the judgment that he or she, given current interest in the kinds of sophisticated enjoyments now pursued, would find life intolerable if paralyzed and unable to speak with the quite different judgment that if the person lost both capacity for those sophisticated enjoyments the desire to pursue them, he or she would find life not worth living. The first judgment might be accurate and the second quite false. Just as it is often difficult for an executive to appreciate the value of the life of the confused, incontinent, socially isolated elderly person who lies about a filthy home, surrounded by thirty wailing cats, so a competent individual may fail to appreciate the value of his or her own future life under greatly altered conditions.

A third and equally significant asymmetry is that in the case of an advance directive, important informal safeguards that tend to restrain imprudent or unreasonable contemporaneous choices by a competent individual are not likely to be present, or if present, to be as effective. If a competent patient refuses life-sustaining care, those around the person who are responsible for care can and often do urge the patient to reconsider his or her choice. The well-known bias of health care professionals toward prolonging life, as well as their tendency to be optimistic about prospects for relief or cure through further treatment, can sometimes prevent a patient from giving up too soon. In some cases, an expression of concern by the family and the health care team — a clear message that they believe the patient's life is valuable and that they are committed to the person — can correct for distortions in the patient's decisionmaking due to the depression of the loss of self-esteem that often accompany serious illness.

Although the decision to refuse or accept treatment must ultimately rest with the competent patient, everyone may benefit from a health care system in which the patient who refuses life-sustaining care or treatment must face a degree of opposition in doing so. So long as those who express initial disagreement with the decision do so by rational discussion rather than manipulation or coercion, the patient's self-determination is respected. This sort of initial opposition, as a safeguard against imprudent decisions to forego treatment, is unlikely to come into play as forcefully, if it occurs at all, during the process of drawing up an advance directive. The decision to forego life-sustaining treatment is a remote and abstract possibility, the more contemplation of which is unlikely to illicit the same protective responses that are provoked in family members and health care professionals when they are actually confronted with a patient whom they believe should live but who chooses to die.

These three differences between the contemporaneous choice of a competent individual and an advance directive support the conclusion that more confidence should be accorded to the assumption that an individual is the best judge of his or her own interests in the former case than in the latter. To the extent that the case for self-determination rests upon this assumption, this right is of narrower scope in the case of advance directives than for the contemporaneous choice of a competent patient. Even if a competent patient has the right to refuse life-sustaining treatment or care when others believe it is fundamentally contrary to the patient's own interests to do so, it does not follow that the same choice ought always to be respected if embodied in a valid advance directive.

The most troubling case for according advance directive absolute authority would be of the following sort. An apparently valid advance directive specifies that no life-sustaining treatment, including antibiotics, are to be used on the individual if he or she suffers a serious loss of cognitive function. The patient does suffer a serious loss of cognitive function due to a discrete neurological injury, such as a stroke: The person is now moderately mentally handicapped. However, the patient is otherwise healthy, and apparently quite happy. Then the patient develops a life-threatening pneumonia. Following the advance directive will result in the easily avoidable death of a happy and healthy, though mentally handicapped individual. Cases like this challenge the assumption that the moral authority of advance directives may never be limited on paternalistic grounds.

Yet, the combination of factors that make cases such as this one so troubling will probably be quite rare. An individual who is in the advanced stages of terminal cancer or of Alzheimer's disease is not an otherwise healthy person whose only disability is a loss of cognitive function. Moreover, many, if not most, of these individuals do not appear to be happy — as many mentally handicapped people apparently are — but instead suffer anger, frustration, and terror resulting from disorientation and confusion, as well as physical ailments.

It seems unlikely, then, that many cases will arise in which this special limitation in the moral authority of advance directives should actually come into play. In most cases, the expressed intention of the individual who issues an advance directive is to avoid a prolongation of life that would involve burdens that are disproportionate to benefits, not to withhold treatment or care that would clearly serve the individuals best interests. If this intention is clearly expressed in the advance directive, then there will be no need to override it on paternalistic grounds. Therefore, acknowledging in principle this special limitation on the moral authority of advance directives need not, in principle, undercut the authority and usefulness of these directives in general. At least in cases in which doing so would not be clearly contrary to the patient's most basic interests, an advance directive, like the contemporaneous choice of a competent patient, can provide a justification for withholding any form of life-support including feeding, whether by artificial means or otherwise.

The central dilemma for public policy is that of developing institutional safeguards that adequately reflect these moral reservations about advance directives without so weakening their authority as to rob them of value. If the conditions for issuing an advance directive are made too demanding, or if physicians and families are granted wide discretion to override them, then the advantages that made them attractive in the first place will be lost.

Conclusions: The Scope and Limits of the Moral Authority of Advance Directives

Advance directives are subject to all the same limitations as the right of a competent patient to refuse medical care and treatment. In neither case, for instance, is there a right to be killed. Nor is there a right to demand services. Hence if an individual stated in an advance directive that he or she wanted all possible means of support continued for as long as there is any prospect of survival, no matter how small, the advance directive itself would not create any obligations on the part of others to supply the services in question — unless the individual had made arrangements to pay for them.

And, like the right of the competent patient, the right to determine future treatment are care decisions by an advance directive is not a right to impose significant health risks to others.

Further, even in cases in which there is an ongoing physician-patient relationship that creates special duties to provide care on the part of the physician, the competent patient has no right to demand unorthodox treatment or treatment that falls below the accepted standard of care, regardless of whether the patient chooses such treatment through a contemporaneous decision or in an advance directive.

The moral authority of advance directives is, however, in principle subject to one further limitation that does not apply to the competent patient's right to refuse care or treatment. Because the arguments from the value of well-being and self-determination that support the competent patient's right have less force in the case of advance directives, it may sometimes be appropriate to refuse to implement an advance directive when doing so would result in the death of an individual who, though impaired, would with proper care and treatment lead a life that clearly contains more pleasure and enjoyment than suffering and pain.

It is important to note, though, that a social and legal policy that acknowledged that advance directives may in some rare cases be overridden on paternalistic grounds might be subject to serious abuse. The long struggle to guarantee the rights of competent patients provides ample evidence that many physicians tend to be overly paternalistic. Even if a paternalistic limitation on the authority of a small class of advance directives is justifiable in principle, efforts to restrict the limitation to just those cases in which it is appropriate may fail. If this occurs, then must of the value of advance directives as a means for exercising individual self-determination would be lost.

The most urgent ethical problems concerning advance directives is the need to ensure that the conditions of validity are met and to embed the practice of implementing them in a set of effective but not unduly cumbersome institutional safeguards that will minimize the effects of conflicts of interest. In the case of proxy advance directives (durable powers of attorney), the problem of conflicts of interest is especially acute because the person who is close enough to the principal to be chosen as a proxy is most likely to have interests that are in conflict.

The most highly developed existing instance of a proxy advance directive — the Durable Power of Attorney for Health Care created by statute in California — is likely to be duplicated, at least in general outlines, in many other jurisdictions in the next decade. The Durable Power of Attorney for Health Care allows the individual great flexibility in planning his or her future and can avoid costly, time-consuming, and intrusive guardianship proceedings that might otherwise be required for certain treatment decisions. At the same time, it bestows on private individuals unprecedented freedom to make life-or-death decisions for others, and also provides a great measure of protection to physicians who carry out the choices those individuals make. Thus the very features that make the Durable Power of Attorney for Health Care Care so attractive also create a special need for carefully crafted institutional safeguards. These more concrete, practical issues will be addressed in detail in chapter 4.

The Substituted Judgment Standard

Even if the considerable attractions of the advance directive approach are fully acknowledged, substantive standards for decisionmaking will still be needed, not only for cases in which there is no directive to rely upon, but also for cases in which the advance directive does not provide adequate instructions to cover all decisions that must be made. In the case of proxy advance directives, the same respect for self-determination that justifies the recognition of the authority of an advance directive in the first place implies that the proxy ought to attempt to make decisions according to the Substituted Judgment Standard — choosing as the incompetent individual would choose were he or she competent. Where sufficient evidence is lacking to exercise substituted judgment, the proxy ought to rely on the Best Interest Standard, discussed in detail in the next section.

Where there is no advance directive, there is no one Guidance Principle appropriate for all cases. Several recent influential court rulings have failed to recognize this fundamental point, applying the Substituted Judgment Standard to cases in which it was wholly inappropriate.

The source of this error lies in two landmark judicial decisions: The New Jersey Supreme Court's ruling in the Quinlan case (In re Quinlan, 1976) and the Massachusetts Supreme Judicial Court's ruling in the Saikewicz case (Superintendent of Belchertown State School v. Saikewicz, 1977). Both cases appeared to hold that substituted judgment is the appropriate Guidance Principle for decisionmaking for all incompetent patients (at least where no valid advance directive is available). Their assumption was that all incompetent individuals have the same rights as competent persons, including the right to refuse medical treatment. Reasoning that only through substituted judgment could a surrogate exercise of this right be achieved for those who cannot exercise it for themselves, the Quinlan and Saikewicz courts concluded that to fail to apply substituted judgment to an incompetent would be to deny him or her a fundamental right.

What the courts failed to appreciate is that a surrogate exercise of the right of self-determination is not possible for incompetent individuals in two types of cases. In the first, although substituted judgment is in principle applicable because the incompetent patient was at some earlier time competent and capable of making a decision about the treatment or care in question, sufficient evidence of what the patient would choose now, if competent, is lacking. This may often be the case simply because many individuals have not clearly expressed the relevant preferences prior to the onset of incompetence or because they have expressed relevant but contradictory preferences. For such individual, no responsible application of substituted judgment — and hence no surrogate exercise of the right of self-determination — is possible. By tenaciously clinging to the assumption that a failure to exercise the right of self-determination on the patient's behalf is to discriminate against the incompetent individual, the courts have sometimes stretched beyond reason what counts as sufficient evidence for a decision according to substituted judgment.

The Spring case shows how far this lowering of standards of evidence or prior wishes has progressed 9In re Spring, 1980). Earl Spring, an allegedly senile 78-year-old man suffering permanent total kidney failure, was expected to live about 5 years if his dialysis treatments, which had begun before he became senile, were continued. His wife and son petitioned a Massachusetts probate court for authorization to terminate the dialysis. The Appeals Court found that Spring, if competent, would not wish to be kept alive in his present condition.

The authors of an amicus curiae brief correctly observed at the time that "the evidence provided by family members, in an attempt to indicate what Mr. Spring would choose, is virtually non-existent." (Annas and Glantz, 1980). The only consideration adduced was that Mr. Spring was now unable to live the active, vigorous life he had enjoyed when he was competent. But there are convincing reasons for rejecting this vague and anecdotal evidence (Annas and Glantz, 1980):

> It is almost always true as people get older that their level of activity declines, and is often severely curtailed. It does not follow from this that such a person would prefer to cease living because of the curtailment of such activities.

The second type of error in the application of substituted judgment embodies a more profound confusion. In the case of Joseph Saikewicz, the court attempted to determine whether a 67-year-old man with leukemia — who had been profoundly retarded from birth with an estimated mental age of about 1 and an IQ of 13 — would, if competent, choose to refuse or accept chemotherapy. The court somehow overlooked the fact that Saikewicz's lifelong mental disability was so severe that he was never capable of forming the preferences in question because he lacked the concepts those preferences presuppose.

Yet, to say that Joseph Saikewicz's right of self-determination could not be exercised by proxy because he never had the conceptual capacities required for anyone to infer his preferences about whether or not to be given chemotherapy (or, more generally, to have his life prolonged at the cost of considerable pain) is to trivialize the problem. The very notions of self-determination, and hence of a right of self-determination, only apply to beings who have, or at least have the potential for developing, certain rather complex cognitive functions: the ability to conceive of the future, to discern alternative courses of action, and to make judgment about their own good. Above all, it makes sense to ascribe a right of self-determination only to beings who are capable to conceiving of themselves as agents — beings distinct from, and capable of changing, their environment (English, 1983; Tooley, 1983; Warren, 1982; Feinberg, 1982). Instead of clearly acknowledging the inapplicability of Substituted Judgment in cases like that of Joseph Saikewicz, the court made a heroic but confused attempt to ascertain the conceptually sophisticated preferences of an individual who never possessed the requisite concepts, in order to protect a right of self-determination that could never be ascribed coherently to him.

Scope and Limits of Moral Authority

As a legal standard, substituted judgment first emerged in probate court rulings concerning financial decisions on behalf of incompetent individuals (President's Commission, 1983a). These rulings recognize an important limitation on substituted judgment. A gift may be made to another from an incompetent's estate if the ward would have made this gift if competent, but only if the gift is not so large that it would deprive the ward of the basic necessities of life, even if the ward, if competent, would have been more generous. Presumably the rationale for this limitation is that the inherently speculative nature of substituted judgment, along with the vulnerable position of the incompetent, require that substituted judgment may not be used to justify a course of action that serves the interests of others at the expense of the ward's basic interests. It is important to note that this limitation does not reduce substituted judgment to best interest: a decision may satisfy the rather minimal condition of not being clearly contrary to the individual's basic interests and yet not be in his or her best interest.

The justification for this limitation on the authority of substituted judgment becomes stronger once the nature of this standard is examined more closely. First of all, the moral justification for doing what the patient would choose if competent, as indicated, is that doing do shows respect for his or her former autonomy, both as something valuable in itself and as a means toward promoting the person's well-being. But acting in accordance with prior preferences shows respect for autonomy only if those preferences were voluntary. Hence evidence that the individual, when competent, was subject to duress or manipulation that affected the preferences in question undercuts reliance on those preferences for the exercise of substituted judgment. Similarly, the fact that the individual when competent expressed a preference for withholding certain care or treatment is not basis for substituted judgment if there is reason to believe that those preferences were seriously uninformed.

Furthermore, it is worth emphasizing that the judgment an individual would choose a particular course of action if competent must rest on evidence about other closely analogous choices he or she actually made when competent or, more likely, upon evidence about preferences expressed when competent (not upon evidence that when competent the person did choose this course of action, which would be an advance directive, and hence obviate the need to appeal to substituted judgment).

The crucial point here is that evidence concerning preferences does not have the same moral weight as evidence about a deliberate choice. A deliberate choice is an act of will; a preference is merely a pro-attitude, a desire to have one thing rather than something else. Sometimes a person deliberately chooses not to do that which he or she prefers, either out of prudence or because the person thinks it would be morally wrong to do so. The contemporaneous choice of a competent individual under conditions of informed consent — like the issuing of an advance directive under analogous conditions — is an act of will, not the mere expression of a preference.

The practical import of the distinction between an expression of preference and an act of will may be seen by contrasting the moral (and legal) significance of two uttering reply to the question, "Will you take this woman to be your wife?" Under certain circumstances, the question might be taken as a straightforward factual inquiry about what a person will in fact do at some time in the future. And, absent any assumption of deceit or duress, the prediction made in answering, "I will" might reasonably be taken as evidence of a man's preferences for the woman in question. However, in other circumstances (when standing at the altar before witnesses) the same utterance ("I will") would not only express a preference but also constitute an act of will — in this case the making of promise — which has different moral implications.

Similarly, while a competent person's statement that he or she would not wish to be sustained if severely brain-damaged may be an accurate expression of preferences at that time, it may not have the same moral force as the deliberate choice, or act of will, of a competent patient who, in the presence of witnesses and after serious discussion, explicitly chooses not to have a particular treatment. In so choosing, the individual is waiving his or her right to the care or treatment in question and thereby releasing others from their duty to provide it. A mere expression of preference may not be sufficient to waive a right or release anyone from an obligation.

One final observation adds additional weight to the case for limiting substituted judgment by the condition that the decision not be clearly contrary to the incompetent's basic interests, at least with regard to medical decisions. Many of the most critical decisions, including those concerning termination of life-sustaining treatment, are made in tertiary care facilities. The physician and other members of the health care team in such setting's often are not well acquainted with the patient's preferences and "value history" when he or she was competent. If this is the case, then the health care professionals treating the patient will not be in a position to serve as an independent check on the accuracy of the family's claims about what the patient would want if competent. This is very troubling because the family, more than anyone else, may have a serious conflict of interest that distorts their testimony about what the patient would want.

Granted the potential for deliberate abuse or unintended bias, safeguards are clearly needed. One approach is to extend to medical decisions the "basic interests" limitation that probate court law places on financial decisions. An alternative is to place no limits on the scope of the substituted judgment decision itself but to construct institutional safeguards to avoid undue reliance on the family's claims about what the patient would want if competent (or upon the claims of the institutional caretakers of patients who have no family).

It would be a mistake to assume that the only adequate institutional safeguard is to require that substituted judgment must be exercised by a judge or by a court-appointed guardian ad litem in all or even most cases. As will be shown later in this paper, some of the safeguards provided by direct judicial involvement can be achieved by less formal — and less intrusive and cumbersome — institutional arrangements.

The Best Interest Principle

In cases in which there is no valid advance directive and in which substituted judgment is inapplicable, the Best Interest Principle ought to guide decisionmaking for the incompetent individual. The qualifier "best" signals the complex and comparative nature of the judgment: Some interests (such as the interest in avoiding death or chronic pain) are generally more important than others in that advancing them makes a greater contribution to the individual's good, and a particular decision can advance some of the individual's interests while thwarting others. Thus the Best Interest Principle instructs us to determine the net benefit for the patient of each option, assigning different weights to the options to reflect the relative importance of the various interests they further or thwart, then subtracting costs or "disbenefits" from the benefits for each option. The course of action to be followed, then, is the one with the greatest net benefit to the patient. The mere fact that a treatment would benefit the patient is not sufficient to show that it would be in the individual's best interests, since the costs to the patient — in suffering and disability — may exceed the benefit (Feinberg, 1984' President's Commission, 1983a).

Since the effects of medical decisions and decisions about the incompetent person's financial assets are sometimes interdependent, a package of decisions must be considered, rather than individual decisions in isolation. This greatly complicates matters and, as indicated later, limits attempts to divide the labor among surrogates according to their area of expertise.

The Best Interest Principle is clearly patient-centered because it focuses primarily upon the current and future interests of the incompetent individual. As such it must take into account "quality-of-life" judgments. Whether a particular treatment or even the provision of nutritional support is in a patient's interest depends upon whether life under the conditions that would exist if the care in question were provided would be worth living for the patient. Quality-of-life judgments are mandatory because whether life would be worth living for the patient depends not only upon the length of time that life would be extended but also upon the character of the life for the patient during that period. The factors that must be considered will vary, depending upon the physical and cognitive capacities of the individual. For these with severely reduced cognitive capacities, life may be worth living if there is a balance of simple pleasures or contentment over pain and discomfort.

Several influential court rulings, including Saikewicz and the ore recent Conroy decision, have purported to exclude quality-of-life considerations altogether from decisionmaking for incompetents. Quite understandably, many physicians and families have taken this exclusion to be inhumane because it seems to overlook the important fact that in some cases prolonging life can subject the patient to burdens that are disproportionate to any benefits that person receives (Relman, 1978).

The courts that have attempted to exclude quality-of-life judgments and those that have criticized them for doing so have all failed to distinguish carefully two very different sorts of quality-of-life judgments. The first may be called the social worth or interpersonal sense. To make such a quality-of-life judgment is to assign some comparative value to the life of an individual — to rank the worth of that individual relative to the worth of others, usually for the purpose of calculating the costs and benefits of expending resources upon the person. The second sense of quality of life may be called the intrapersonal or noncomparative sense, in which a judgment is made about the value or quality of an individual's life to that individual, regardless of how society or would-be calculators of social utility evaluate it (Buchanan, 1979).

Nothing in the reasoning the Saikewicz court actually went through in making its decision appears to exclude intrapersonal quality-of-life considerations. Indeed, the only coherent reconstruction of that ruling is that is requires that interpersonal quality-of-life judgments be made in the effort to determine what the patient would choose, were he or she competent, or, where this cannot be ascertained, what would be in his or her best interest. Since Joseph Saikewicz had never been competent, no judgment could be ventured as to what he as an individual would choose were he competent. Instead, the appropriate task for the Massachusetts Supreme Judicial Court would have been to recognize explicitly the inapplicability of Substituted Judgment and to affirm the lower court's judgment that treatment was not in Saikewicz's best interest.

Although it claimed to be exercising Substituted Judgment, the Massachusetts Supreme Judicial Court in fact seems to have based its decision to allow treatment to be withheld on the fact that the quality of Saikewicz's life to him would be extremely poor during the period of its prolongation, thus tacitly appealing to his best interest. The usual suffering produced by chemotherapy would be increased by the patient's inability to comprehend what was being done to him (Saikewicz, 1977, pp. 430-432):

> He . . .would experience fear without the understanding from which other patients draw strength. The inability to anticipate and prepare for the severe side-effects of the drugs leaves room only for confusion and disorientation.

This passage from the *Saikewicz* ruling expresses a quality-of-life judgment of the difficult to understand the court's decision against treatments in this case except as being based on such a judgment. More generally, no reasonable interpretation of acting in the interest of an incompetent, or of doing what he or she would choose, were he or she competent, could exclude this sort of quality-of-life judgment.

How, then, can this interpretation of the *Saikewicz* case be reconciled with the court's statement that quality-of-life judgments are *not* to be allowed to influence the decision? The answer is quite simple: The quality-of-life judgments that the *Saikewicz* court correctly sought to prohibit were *interpersonal* (social worth) judgments, not *intrapersonal* judgments.

Beyond the Scope of the Best Interest Principle: Permanently Unconscious Patients

In some patients neurological damage is so extensive and irreversible that the application of the Best Interest Principle — and with it the concept of quality of life — becomes extremely tenuous. Attempts to apply this principle to those in a persistent vegetative state — who are permanently unconscious but not legally dead because some lower brain function remains — have sometimes resulted in confusion and in the erroneous conclusion that such individuals must be maintained indefinitely on life-sustaining measures such as respirators and nasogastric tube-feeding.

A patient in a persistent vegetative state (lacking all consciousness) will experience no pain or discomfort from life-sustaining efforts. So it cannot be said that it is in the patient's best interest to withhold such systems because the pain and discomfort would outweigh any benefit to the individual. Instead, the Best Interest Principle, if taken literally, might seem to require perpetual life-sustaining efforts for everyone in a persistent vegetative state. This conclusion was in fact drawn by a guardian ad litem recently appointed by a Massachusetts court to represent the interests of a Mr. Brophy, a 47-year-old former firefighter who lapsed into a persistent vegetative state after surgeons attempted to repair damage caused by an aneurysm that had burst in his brain 2 years earlier. The guardian ad litem, who challenged a request by the patient's wife to remove a feeding tube, is quoted as saying, "I can't believe it is in Mr. Brophy's interest to be starved to death" (Boston Globe, 1985).

His conclusion is incorrect, however, for two reasons. First, if the testimony of his family and friends is accurate, Brophy had expressed a very strong and clear desire not to be maintained under such conditions. If, employing the whole-brain concept of death, it is assumed that Brophy is not dead, then it can be said even now that it is in his interest not to be maintained, if avoiding a prolongation of irreversibly unconscious life was extremely important to him when he was conscious. Second, since he derives no benefits from the bare preservation of his vegetative functions — being permanently unconscious — there is no current interest in gaining such benefits that could outweigh his previously expressed interest in avoiding a prolongation of permanently unconscious life. So the guardian ad litem's conclusion that it cannot be in the patient's interest to die of malnutrition is simply false.

In Brophy's case, again assuming that the testimony of his family and friends is correct, the appropriate Guidance Principle is substituted judgment. But in the Quinlan case — and others in which a decision must be made concerning a permanently unconscious patient who had not previously expressed a desire not to be maintained — the appropriate Guidance Principle is best interest. And it is difficult to see how ending a patient's life — a life without suffering or discomfort — could be in the patient's best interest. Thus, the Best Interest Principle seems to forbid the withholding of support of cases in which the individual when competent did not express a desire to be sustained in a persistent vegetative state.

This unsettling result arises from the unexamined assumption that the notion of interest relevant to the Best Interest Principle applies to the individual in a persistent vegetative state. If these individuals can be said to have interests at all, this is only because the word "interest" is used in a very attenuated sense. A similar attenuated sense of the word may apply when speaking of what is good or bad for rudimentary forms of animal life or plants (saying, for instance, that sunshine is good for a rosebush). Even when indulging in the somewhat misleading language of saying that a rosebush has interests (rather than simply saying that some things are good for it and others not), it does not follow that there is any moral obligations to promote its "interests" (or to do what is conducive to its good).

Whether the rosebush's "interests" are promoted or not, indeed whether it lives or dies, does not matter to the rosebush — because it lacks (and always will lack) consciousness of any sort. And the fact that it does not matter to the rosebush whether it lives or dies matters to us. We do not have positive obligations, obligations to use scarce human and natural resources to promote the "interests" of (to do what is good for) beings whose good can never matter to them. The Best Interest Principle, however is a principle that expresses a positive obligation, a duty to do what best promotes someone's interests or is most conducive to his or her good. As such, the Best Interest Principle does not apply to beings who have no capacity for consciousness and whose good can never matter to them, and this includes human beings who are in a permanent vegetative state.

It might be suggested that so long as the probability is greater than zero that the prognosis is erroneous, there is a perfectly robust, unattenuated sense of "interests" that is applicable — namely, the interest that an individual has in returning to a cognitive state should he or she become comatose. If there is a chance of recovery, be it ever so slim, the Best Interest Principle might be thought to yield the result that every comatose patient must be sustained for as long as possible. Given the tremendous value of the favorable outcome for the individual, acting in the patients Best Interest seems to require sustaining him or her indefinitely, so long as there is any hope at all. Such an application of the Best Interest Principle would exacerbate the already grievous dilemmas of allocating scarce medical resources, especially since advances in medical technology are making it possible to sustain larger numbers of individual in a persistent vegetative state for longer periods of time.

However, this effort to apply the Best Interest Principle to individual who are believed to be permanently unconscious overlooks an important factor. To determine what maximizes the patient's expected net benefit, we must not only consider the (very small) probability that he or she will return to a cognitive, fully functional state, we must also take into account the very high probability that the individual will be severely disabled is he or she ever regains consciousness (Rosenberg, et al., 1977; Cope, 1980; Peterson, 1980). The only well documented cases of adult's regaining consciousness after having been judged by experts as being permanently unconscious illustrate this point graphically: A person is paralyzed in three limbs, emotionally unstable, and totally dependent on others for the remainder of his life; the other is severely depressed and remains in the so-called locked-in condition, completely paralyzed except for the ability to blink his eyes (President's Commission, 1983a).

Even ignoring the high probability that disability will be severe, indeed almost total, if the patient regains consciousness after an extended period in a vegetative state or deep coma, it would still not follow that a commitment to the Best Interest Principle in other contexts requires that every effort be made to maintain such patients for as long as possible so long as there is any possibility, no matter how minuscule, that they will recover. Just as an individual or a society is not obligated to continue the search for a lost hiker or a shipwrecked sailor indefinitely, regardless of cost, so the Best Interest Principle cannot be viewed as committing society to ceaseless efforts to "save" an individual whom we believe — beyond a reasonable doubt — to be permanently unconsciousness.

It should be clear that the Best Interest Principle, properly understood, does not require that permanently unconscious patients be sustained indefinitely. It does require, however, that such individuals be maintained on life-sustaining long enough to make reliable prognoses that consciousness will not return (Steinbock, 1983). But one this has been done, the fact that the prolongation of vegetative functions brings no benefit to the patient justifies withdrawal of life support. The proper questions for such patients then is not "Would withdrawal of life support best serve the patient's interest?" but rather

"Would continued support provide any benefit?" The Best Interest Principle applies, strictly speaking, only to cases in which treatment or nontreatment can either serve or thwart the patient's interests. Permanently unconscious patients have no interests, or at least no interests of the sort that the Best Interest Principle is designed to protect.

The Individual's Interest in the Good of Others

Several important court decisions have addressed the issue of whether, in determining what would be in the best interest of an incompetent individual, an individual's interest in the good of others ought to be considered (Strunk v. Strunk, 1969; Hart v. Brown, 1972; Little v. Little, 1979; Robertson, 1976). The cases in question have involved minors or mentally handicapped nonelderly adults who were potential organ or bone marrow transplant donors for relatives. Those seeking permission for the transplantation argued that it was in the interest of the incompetent to preserve the life of the relative, either because failure to do so would cause psychologically damaging guild or, somewhat more plausibly, because the loss of the relative would deprive the incompetent of a satisfying and supportive relationship.

Although these cases involved younger individuals, it is not hart to see how the issues they raise extend to elderly incompetents. The President's Commission on Medical Ethics drew this implication, suggesting that since most people have an interest in the welfare of their families or closest associates, the patient's interest in avoiding severe financial and emotional burdens for his or her loved ones ought to count in determining whether termination of treatment is in the incompetent's best interest (President's Commission, 1983a). Aware of the potential for abuse, the Commission went on to suggest that — at least in cases in which acting according to what is taken to be in the individual's interest in the good of others is contrary to that person's important self-regarding interests — a high standard of evidence should be required for showing that the individual does in fact have an interest in the good of others (President's Commission, 1983a).

Although it is correct to note that the potential for abuse if great, the approach the Commission recommended is flawed. If there were sufficiently weighty evidence that the individual did take a strong enough interest in the good of others to justify a decision that runs contrary to the patient's self-regarding interests, then this evidence would presumably be strong enough to justify the use of substituted judgment instead of the Best Interest Principle. It appears, then, that when decisionmakers must rely on the Best Interest Principle (rather than an advance directive or substituted judgment), the determination should focus on the individual's self-regarding interests, not upon his or her alleged interest in the good of others.

The Dependence on Institutional Options and Other's Interest in the Patient

Whether a particular decision would be in the best interests of an individual often crucially depends on what institutional options are available and on the interests and preferences of others with whom the individual is closely associated, even if he or she does not take an interest in their well-being. It might be said that psychosurgery or a massive does of tranquilizer that reduces a patient to docility at the expense of his or her personality are nonetheless in the patient's best interest because they eliminate behavior that would lead to serious abuse or neglect by caretakers or retaliation by fellow patient. Similarily, some would justify withholding life-sustaining treatment from a severely demented elderly individual with no family on the grounds that it would be in that individual's best interests to live in an inadequately funded state institution that is little more than a "human warehouse."

These two examples vividly illustrate the enormous potential for abuse inherent in construing the Best Interest Principle so as to include in the patient's interests the effects of the preferences and interests of others, or the effects of defective institutional arrangements on his or her interests. It would be a tragic irony if adherence to a principle designed to protect the individual incompetent served only to perpetuate attitudes and social practices that systematically disadvantage incompetents as a class.

On the other hand, neither the attitudes of others nor the defects of existing institutions can be ignored in determining what is in the incompetent's best interest. In applying the Best Interest Principle, a thin line must carefully be tread between passively accepting existing attitudes and institutions, which in some cases severely constrain the good that can be done for the elderly incompetent, and making a decision as if those constraints did not exist.

AUTHORITY PRINCIPLES: WHO SHOULD DECIDE?

The need to fix primary decisionmaking authority and responsibility is most obvious in cases in which the appropriate Guidance Principle is either best interest or substituted judgment. Instructional directives are by definition an attempt to make the individual, when competent, the principal decisionmaker, while the purpose of a proxy advance directive is to identify a decisionmaker in advance. However, since instructional advance directives can neither cover every contingency nor be fully self-explanatory, someone must be identified as having principal responsibility for interpreting and applying the instructional advance directive as choices arise. Only proxy advance directives provide an answer to the question of who the surrogate decisionmaker is to be and, as noted earlier, only a very small minority of persons currently issue such directives.

Unless there is a clear locus of authority, decisionmaking is liable to be lacking in coherence, continuity, and accountability. Nevertheless, it is important to recognize that regardless of which Guidance Principle is followed, decisionmaking is likely to be more or less shared. The principal decisionmaker will not, and generally should not, operate in isolation. Physicians traditionally have played an important role in shaping decisions because families have often relied heavily on their advice, deferring to the physician's technical expertise, but probably also because families often wish to diffuse the responsibility for making painful decisions under conditions of uncertainty. Attorneys, bank trust officers, and other financial advisors may exert considerable influence on their client's decisions for similar reasons. One of the main conclusions to be drawn about Authority Principles is that shared decisionmaking — if properly structured by appropriate institutional arrangements and procedural safeguards to ensure accountability and combat conflict of interest — is highly desirable. The task at hand, therefore, is to ascertain who the principal decisionmaker should be and to delineate the structure within which that person should operate.

The Family as Decisionmaker

In general, the appropriate presumption is that the family of the incompetent individual is to be the principal decisionmaker, except in those emergency situations in which the family cannot be consulted without a delay that puts the patient at risk. The "family" is usually considered to be the individual's closest biological relations or spouse. However, it is essential to recognize that the fundamental notion here is broader. For purposes of surrogate decisionmaking, the family is whomever the individual is most closely associated with. This point is especially important at a time when alternatives to marriage and the nuclear family are becoming more common. Neither the law nor less formal practices on the part of physicians or attorneys should be allowed to discriminate against those who have chosen to participate in nontraditional intimate associations.

The chief reasons in support of the presumption that the family is to serve as surrogate decisionmakers are both obvious and compelling. As the President's Commission noted, the family is generally both most knowledgeable about the incompetent individual's good and his or her previous values and preferences, and most concerned about the patient's good (President's Commission, 1983a). Furthermore, especially in a society in which impersonal relationships have replaced most other forms of community, participation in an intimate association is one important way in which individuals find or construct meaning in their lives. Since intimate relationships can only thrive under conditions of privacy, society should be reluctant to intrude in the family's decision concerning its own members, unless others are adversely affected.

The presumption in favor of the family as surrogate is stronger in the case of decision about medical treatment or care than in those about the disposition of the incompetent individual's financial assets. There are two reasons for this: 1) there is more likely to be a serious conflict of interest in the latter case (as noted earlier, and 2) the context in which the more serious medical treatment or care decisions are usually made typically provides significant safeguards to inhibit decisions that promote the family's interest at the expense of the incompetent person's welfare — safeguards that are not usually present in decisions regarding the incompetent's financial affairs.

The professional methods of health care providers, which tends to focus their concern primarily on the welfare of the patient, as well as widespread fear of legal liability should they fail to safeguard patients, provide significant safeguards against self-interested decisionmaking by the family in the medical context. Moreover, the relatively public institutional environment in which many of the more serious medical decisions are made, especially in large tertiary care facilities, makes it more likely that at least the most flagrant abuses will not go undetected. In contrast, decision about the management of an incompetent's estate and about where he or she shall live and with whom the individual shall associate — though as momentous for the individual as some of the most serious medical decisions — are often made in ore private settings with little or no institutional safeguards or accountability. As will become apparent in chapter 4, current procedures for guardianship and conservatorship do not always provide adequate protection for the incompetent elderly against the conflicting interests of family members who seek to control their financial affairs.

Physicians and Judges as Decisionmakers

The presumption that the family is to be the principal decisionmaker for the incompetent concerning medical care and treatment has been challenged from two quite different perspectives. On the one hand, some physicians have held that the physician should assume this role (Relman, 1978). On the other hand, some legal scholars have contended that, at least for critical medical treatment decisions, neither families nor physicians, but only judges, should decide (Baron, 1979). Both the medicalization and judicialization approaches have been criticized in detail (Buchanan, 1979). This section summarizes the main considerations that favor rejecting these competing models of decisionmaking authority and endorsing the presumptive family authority view.

The chief difficulties with the view that the physician should be the principal decisionmaker for the incompetent patient are: 1) that it overestimates the knowledge that physicians usually have of their patient's interests and values, while underestimating the families' ability, when properly informed, to make reasonable decisions; and 2) that it confuses medical judgments, which physicians' special training uniquely qualifies them to make, with moral decisions, for which physicians as such possess no special credentials. The judgment that an individual in the advanced stages of Alzheimer's disease is in a persistent vegetative state is a medical judgment expressing a prognosis. The judgment that a patient who is in vegetative state may be allowed to die is not a medical, but rather a moral, judgment.

The confusion between medical and moral judgments stems in part from a failure to sort out different kinds of costs and benefits that must be taken into account in making a judgment about what is best for a patient who cannot express his or her own preferences. Whether a certain treatment would be in the best interest of the patient depends not only upon the medical effects of treatment but also upon the relationship between those effects and the interests and previously expressed values of the patient. Physician's professional expertise makes them more knowledgeable about the former, but not about the latter.

Disagreements Within the Family

In some cases, disagreements among family members are so intractable that it cannot function as a coherent decisionmaking unit. If the conflicting members stand in roughly the same degree of closeness to the incompetent, recourse to probate court for a formal determination of guardianship will generally be appropriate.

In other cases, there will be no family or none who is willing to serve as surrogate. this was the case with Joseph Saikewicz — his two sisters were alive but had not had not had contact with him in many years and were unwilling to assume responsibility for the decision to administer or withhold chemotherapy for this profoundly retarded elderly man who was terminally ill with leukemia. As noted earlier, the Massachusetts Supreme Judicial Court issued a ruling that seemed to require that all decisions concerning treatment that is expected only to prolong the life of a terminally ill incompetent patient must be made by a probate court judge after a full adversarial hearing in which a guardian ad litem represented the rights and interests of the incompetent. Just as troubling as the Saikewicz ruling's attempt to extend the Substituted Judgment Principle to an individual who was never competent to make the decision in question was this apparent denial of the presumption that the family of the incompetent is to be the principal decisionmaker. In apparently holding that life-sustaining treatment decisions for all terminally ill incompetents were to be made by judges, the Massachusetts court failed to restrict its ruling to cases, like that of Joseph Saikewicz, in which there is no functioning family.

The requirement of formal judicial proceedings makes especially good sense for individual like Saikewicz, who not only have no functioning family but who also have been long-term inmates of "total institution" such as mental hospitals or prisons. The long and dismal record of neglect, abuse, and outright exploitation of the permanently institutionalized supports the conclusion that — at least for the more serious decisions — the role of surrogate decisionmaker should not be assumed by health care professionals or administrators of the institution in question (except where medical emergencies make this unavoidable).

INTERVENTION PRINCIPLES: ATTEMPTS TO SPECIFY CONDITIONS THAT REBUT THE PRESUMPTIVE AUTHORITY OF THE FAMILY

Adequate protection of the vulnerable incompetent individual necessitates limitations on the family's authority to decide, even in nonemergency situations. The family's role as surrogate ought to be challenged if any of the following intervention conditions is satisfied: 1) the family itself is incompetent to make the decision in question; 2) the family member who is serving as surrogate is acting under duress — for example, the person's decisions are substantially nonvoluntary due to coercive pressure from other members of the family; 3) there is a conflict of interest that is likely to bias the family's judgment in ways that are contrary to the incompetent's important interests; 4) there is evidence of previous neglect or abuse of the incompetent by the family; or 5) the family is disregarding the incompetent's advance directive or, where Substituted Judgment is applicable, the family is acting in a way contrary to the incompetent's previous values and preferences.

Challenges to the Family as Decisionmaker

The person usually in a position to challenge the family's role as surrogate if any of these conditions obtains will vary depending upon the setting in which decisionmaking occurs. In the medical context, the members of the health care team — including physicians, nurses, and social workers — all bear an obligation to see that surrogate decisionmaking is ethically sound. Outside the medical context, it will often be a social service or protective agency case worker or the family attorney who will be in the best position to monitor the family's performance of the role of surrogate. In some jurisdictions, health care professionals and social service personnel have legal duties to report neglect or abuse of the elderly, but as the preceding list shows, not all of the conditions that should trigger scrutiny of the family's fitness to serve as surrogate fall neatly under the heading of neglect or abuse. The moral obligation to protect the defenseless holds regardless of whether it is explicitly recognized in statute law.

The problem of interpreting ambiguous advance directives greatly complicates the task of formulating Intervention Principles that both respect the rights of the surrogate and provide adequate protection for the incompetent individual. Presumably the surrogate should be allowed some discretion in interpreting ambiguous instructions. In particular, the physician should not override the surrogate's decision or seek court appointment of a new surrogate simply because the treatment chosen by the surrogate is not the one that the physician regards as *optimal*. In others words, if competent medical judgment is divided as to which of two or more options for achieving the goal indicated in the instructions is best, the surrogate's choice should be respected. On the other hand, if the physician believes that the surrogates' interpretation of the instructions is outside the limits within which reasonable persons can disagree, the physician's responsibility to the helpless patient requires intervention. The great difficulty, of course, lies in the inherent vagueness of the "reasonable person" standard to which this Intervention Principle appeals. However, the same problem exists in other areas of the law in which the reasonable person standard is employed.

No single answer can be given to the question of what form intervention should taken if any of the conditions listed above is met. In some cases — for example, where there is evidence of abuse — direct notification of the court or of the appropriate government protective agency is in order. In other cases, however, it may be more appropriate to rely, at least initially, upon less formal, less coercive, and less adversarial institutional safeguards for the decisionmaking process. Perhaps the most widely discussed of these is the institutional ethics committee.

The Institutional Ethics Committee

Institutional ethics committees can perform several valuable functions: They can serve as a focus for bioethics education in the institution and the community; they can provide ethics consultation services for staff, patients, and family; and they can serve as a forum for complaints about the surrogate's decisions by the health care team or others, sometime achieving a satisfactory resolution of conflicts without recourse to the courts or other government agencies. Perhaps most importantly, once the rationale for current methods of decisionmaking in the institution is made explicit in the course of the committee's discussions, those practices can be subjected to criticism and revised and improved over time. If properly composed of persons with diverse professional and disciplinary perspectives, including some who are independent of the healthcare institution in which it operates, the committee can improve the impartiality of the decisionmaking process by exposing biases and by calling into question unarticulated assumptions. Since those who appear before the committee will be expected to give reasons for the courses of action they endorse, the opportunity for principled, consistent decisionmaking will be enhanced. Where decisionmaking is either entirely private, with no standards or policy guidelines shared by those working in a particular health care institution, or where it is taken completely out of the hands of the institution and assigned to courts or government agencies, there is little opportunity for developing better models of decisionmaking within the institution.

With respect to the problem of providing safeguards on the family's authority as surrogate, the institutional ethics committee has a dual role. It serves as an initial focus for challenges to the family's decisionmaking authority short of full-scale legal proceedings or official complaints to government agencies. In addition, it acts as a filter to determine which cases ought to be referred to the courts or to government agencies. If, for example, after discussing the matter with the family and the health care team, a committee is unable to resolve a dispute over treatment between two members of a family, each of whom has a reasonable claim to serve as surrogate, then the matter should be referred to probate court for a determination of guardianship. The same action by the committee would be appropriate if its investigations substantiated a report by a nurse that the spouse of an incompetent elderly man — who had been serving as his surrogate — had herself become incompetent to decide for him. There is substantial agreement that the proper role of an institutional ethics committee is not to make treatment or care decisions, but rather to facilitate sound decisionmaking by families and legal guardians, and where this fails to refer cases to court or to protective agencies (Cranford and Doudera, 1984).

It is important to understand that the advantages of reliance on institutional ethics committees are comparative. Even their most enthusiastic supports acknowledge that they are no panacea, and that they are only one element of a complete set of social arrangements needed to assure responsible decisionmaking for incompetent people. The virtue of institutional ethics committees is that they can provide some of the impartiality and critical scrutiny of judicial proceedings in a way that is less cumbersome, less expensive, less adversarial, and less invasive of the patient's and the family's privacy.

Whether or not useful analogs of institutional ethics committees can be developed to enhance nonmedical decisionmaking for the incompetent elderly remains to be seen. At present, institutional ethics committees are not even available as a resource in many hospitals, much less in nursing homes and residential care facilities.

Dealing with Disagreements

Given the lack of institutional ethics committees or alternative intrainstitutional mechanisms for facilitating sound decisionmaking for incompetent patients, the contrast drawn earlier between decisionmaking in medical and nonmedical contexts should not be exaggerated. Allowing the family to exercise broad authority for medical decisions is only acceptable if there are reliable safeguards within the health care institution itself. Where strong disagreement arises among family members and the health care team concerning critical decisions it is more likely that the courts, protective agencies, or other disinterested parties will become involved in an effort to protect the incompetent individual. On the other hand, the mere absence of disagreement among the key parties to the decision is no guarantee of sound decisionmaking. Indeed, perhaps the most troubling case is that in which the family and the physician agree in a biased decision to withhold life-sustaining care or treatment.

In particular, it is crucial that others involved in the care of the patient (including nurses and social workers) be able to voice disagreement with the family and the physician without fear of recriminations. Perhaps the best solution is for the institution to publicize to all staff, patients, and families of patients the existence of an institutional ethics committee or other official formum for discussing ethically controversial cases. As a protection against situations in which all those primarily involved in the case agree but nonetheless make an ethically unacceptable decision, effective mechanisms should be established for the periodic review of patterns of decisionmaking, at least for critical decisions such as those involving termination of life-sustaining treatment. For such intrainstitutional review to serve its purpose, care must be taken to ensure impartiality by including qualified persons who have no direct interest in the case in question. If health care institutions fail to develop adequate internal safeguards, frequent recourse to judicial intervention will be necessary to afford adequate protection to incompetent patients.

DISTRIBUTIVE JUSTICE AND THE CARE AND TREATMENT OF THE INCOMPETENT ELDERLY

The courts, as well as most legal scholars and ethicists, have tended to exclude any explicit role for a consideration of the rights and interests of others in decisions concerning incompetents generally, including the elderly incompetent. This reluctance to face up to the fact that others' rights and interests impose limits upon the moral authority of advance directives, and Substituted Judgment Principle, and the Best Interest Principle represents an understandable and (up to a point) praiseworthy recognition of the extreme vulnerability of the incompetent individual. The key court cases from which these standards have developed and that have shaped the course of the debate have concerned the most momentous decisions — withdrawal or continuance of life-sustaining treatment. A reluctance to depart from a patient-centered approach and explicitly address questions of distributive justice, especially those relating to costs, is all the more understandable in cases of life-or-death decisions for incompetents.

There is another, less obvious, reason why these decisions — and hence the broader ethical debate whose assumptions they have fashioned — have not faced resource allocation issues head-on. The U.S. legal system operates on the "standing case rule," according to which courts are to respond only to actual cases brought by identified individuals. Yet it is in the case of particular decisions that affect the welfare of identifiable individuals that there is the most discomfort about "rationing" scarce resources. Nevertheless, a sound ethical framework for decisionmaking for incompetent individuals must reflect the fact that others have rights and interests as well, and that resources, including medical resources, as scarce.

It is far beyond the scope of this paper to provide a comprehensive theory of distributive justice in decisionmaking for elderly incompetent individuals. Instead, we shall attempt to spell out the main issues such a theory would need to address, and offer partial and tentative answers to some of the more important questions. Once again the emphasis will be on developing a framework for resolving the ethical issues rather than on providing fully developed solutions.

Such a framework must distinguish and then answer several quite different questions. First, to what extent is the treatment of incompetent individuals, or of some classes of incompetent individuals, a matter of justice? The distinction between justice and charity has often been used to draw a line between what care or resources society strictly speaking owes individuals — i.e., what they have a right to — and that which it would be especially commendable or generous of society to provide but to which individuals have no right. This distinction is especially crucial for public policy in general and the specification of legal duties in particular because it is usually assumed that what is required by justice may be enforced if necessary, while charity is usually presumed to be a voluntary matter, largely up to the discretion of the individual.

Second, there is the issue of the division of social responsibility: To what extent ought the individuals themselves when competent, their families, or other private associations bear the responsibility for caring for an elderly incompetent person? To what extent is the responsibility a societal one that ought to be discharged collectively through society's agents in the various levels of government?

Third, assuming that considerations of the rights and interests of others not only maybe but ought to be taken into account in decisionmaking for incompetent elderly people, at what level or in what part of the decisionmaking process ought they to enter? For example, even if it is agreed that the morally responsible allocation of scarce medical resources requires that some services of positive though minimal benefit be withheld from severely demented elderly patients, it does not follow that the decision to do so should be entrusted to the patient's family or physician.

Answers to these questions would supply the minimal structure of that part of a theory of decisionmaking for elderly incompetents that concerns distributive justice. The fully developed theory would provide substantive guidance for the development of institutional arrangements designed to achieve the following ethical goals: a fair allocation of social resources between the elderly and the nonelderly, including a fair allocation of social resources within the elderly population, and a fair sharing of the costs of providing care and treatment for the elderly.

Although each of these questions may seem overwhelming in its scope and complexity it is important to take stock of the implications for issues of distributive justice that already can be drawn from the ethical analysis presented thus far. The discussion of Guidance Principles for decisionmaking for incompetent people itself significantly limits the range of problems and provides some of the material required for solving them.

Relevance of Guidance Principles to Matters of Distributive Justice

The moral authority of both advance directives and Substituted Judgment is based on and limited by the right of a competent patient to refuse care or treatment. As this is a negative right, a right to be free from nonconsensual care or treatment from others. It is not a positive right, a claim to services. Consequently, neither advance directives nor substituted judgment create any new resource allocation issues peculiar to decisions concerning incompetents. An advance directive stipulating that "all" means of life-sustaining treatment are to be used regardless of the quality of the life that would be prolonged would not by itself create any obligation to use social resources, nor would a similar decision reached through substituted judgment. The effect of wider use of advance directives and of substituted judgment would most likely be to withhold life-support and aggressive care more frequently by removing both the moral reservations and the paralyzing fear of legal liability that currently lead some physicians to "over-treat," thus easing the strain on resources.

Furthermore, as argued earlier, a proper understanding of the limits of the Best Interest Principle makes it clear that the continued support of permanently unconscious patients is not ethically required, and that withdrawal of support constitutes no injuries to them. Even if, in subscribing to the whole-brain concept of death, we conclude that such patients are not dead, we can nonetheless exclude them s legitimate competitors for scarce resources because if they have interests at all those interests are so attenuated that the interests of others who can genuienly benefit from the social resources in question should always prevail.

There is, however, an alternative route by which permanently unconscious patients may be excluded from the domain of serious problems of distributive justice in the allocation of medical resources. It is far from inconceivable that the process of conceptual change in response to technological advances that led us from the cardiopulmonary concept of death to the whole-brain concept should eventually push us to a higher-brain function concept of death. If this change — which has already been advocated by a number of ethicists — does occur, then permanently unconscious individuals will be declaired dead and thus will no longer be viewed as having claims on social resources. The only remaining questions of distributive justice concerning this class of individuals would then be much less fundamental and much more tractable. For example, if a person while competent issued an advance directive stating that he or she was to be sustained indefinitely in a persistent vegetative state, this document would have no more legal or moral authority than an ordinary will would have if it stipulated that a brain-dead individual was to be maintained indefinitely on a heart-lung machine. People have a right to have their mortal remains treated with dignity, but not a right that they be forever infused with blood and oxygen — at least not if society is helping to pay the bill.

Key Questions Remain

However, to say that for the most part the Guidance Principles that are appropriate for decisionmaking for incompetent individuals raise no new problems of distributive justice is not to deny that serious problems bound. Even if these principles do not endow the individual with any new positive rights — rights to be provided with services — two questions remain. What general rights to health care, if any, do people have? Does the condition of some incompetent individuals in any way limit such rights, if they exist? Answering these questions, of course, requires nothing short of a general theory of distributive justice in health care and its application to incompetent individuals.

This paper cannot attempt the formidable task of surveying the various competing theories of distributive justice in health care (Daniels, 1985; Buchanan, 1981). Instead, it will concentrate only on two of the key issues with which any adequate theory would have to contend and that are of crucial importance for the subject of this paper. Do the elderly incompetent as a group have a smaller legitimate claim on social resources than others do, or than would justify current levels of expenditures on them? What are the scope and limits of the moral obligations of a spouse or an adult offspring to provide care and financial support for the elderly incompetent?

As will become evident in the examination of current practices in chapter 4, social consensus on the nature of the family's responsibility seems weak, and the law does not provide much guidance here either. Hence an ethical analysis is especially needed as a preliminary to any constructive recommendations for social policy. The first question is no less important and equally fraught with ethical perplexities. When cast, as it so often is, as a choice between favoring one side of the other in a zero-sum competition for resources between the young and well and the elderly and sick, this problem of distributive justice may seem intractable. A major goal of the analysis here will have been achieved if a more constructive approach to the issue of the scope of the incompetent elderly's claim on scarce resources is at least made plausible.

Age and Level of Cognitive Functioning as Criteria for "Rationing" Resources

The term "rationing" unfortunately has narrow associations for some people. Yet the concept of rationing, in its broadest sense, is useful — and in the absence of a better term, indispensable — for approaching some of the most pressing issues in health car. *Wester's Seventh Collegiate Dictionary* simply defines rationing as the careful use of scarce resources, and it is in this very broad sense that the term shall be used here.

A recent book, *The Painful Prescription: Rationing Hospital Care*, applies this broad concept of rationing to health care, noting that rationing occurs whenever the decisions of individual physicians or administrators or the effects of higher level policy choices limit the availability of beneficial care to some patients (Aaron and Schwartz, 1984). Rationing, then, can occur at a number of different levels and the physician need not be the rationer. Indeed, it is possible to utilize institutional mechanisms (such as lotteries or markets) that serve to ration resources without requiring that anyone play the role of rationer. In the broad sense used here, rationing occurs whenever polices and practices are explicitly or implicitly adopted that serve to distribute scarce resources in such a way that some do not receive all of the services from which they could benefit. The discussion in this section concentrates primarily on what may be called macro-level rationing decisions: policy choices to determine what forms of care ought to be available to various groups of patients, as the elements of an adequate level of health care.

Even a broad concept of rationing *health care* resources is not broad enough. Since health is not the only good in life, rationing issues arise with respect to the proper allocation of resources between health care and other good and services. Keeping the breadth of this concept in mind, the question here is whether age or incompetence are ever appropriate criteria for rationing societal resources, especially health care resources.

Those who immediately reject any role for age in macro-level rationing policies characteristically object that some 80-year-olds are more productive and better able to enjoy life than some 40-year-olds, and that consequently age itself is irrelevant. Similarly, it can be argued that since incompetence is simply incapacity to make a decision (or a group of decisions), it is not itself relevant to rationing issues. These initial responses are correct as far as they go, but they do not get at the heart of the matter. More subtle reflection is needed to determine whether there are morally relevant factors that ought to be taken into account in rationing that are sufficiently reliably correlated with age so that age could reasonably serve as an indication of them. Similarly, the issue worth discussing is not whether incompetence itself gives an individual a smaller claim on scarce resources, but rather whether cognitive functioning that falls below some specified level is either itself morally significant for questions of rationing or is reliably correlated with other conditions that are relevant.

On the one hand, there seems to be a rather widespread worry that too much is being spent on the terminally ill, most of whom are elderly, and especially upon those who are not only expected to live only a short time but who will spend that time in a condition of severely reduced cognitive functioning — in particular, those who are severely demented, yet not completely and permanently unconscious. On the other hand, many have reacted with shock and indignation to reports that in some industrial countries — in particular, the United Kingdom and Sweden — life-sustaining technologies such as hemodialysis are routinely withheld from patients who are "senile" or over age 55.

A great deal of what many find so troubling about the idea that age or level of cognitive functioning should play a role in rationing is the fear that it results from a failure of the young and fit to appreciate the value that life — even a short time afflicted with disabilities — can have for some people. There is also a natural tendency to assume that if age or level of cognitive functioning are allowed to play any role, then rationing becomes a zero-sum game, a desperate conflict in which one group can only benefit at the expense of the other.

The "Rational Insurance" Approach

There is, however, a way of conceptualizing rationing issues — at least at the level of policies for allocating societal resources among different forms of health care — that avoids basing the distribution of resources on any one group's distinctive and parochial perspective on the quality of life, and that also rejects the assumption that the distributional task is a zero-sum game. According to this view — which may be called the rational insurance or prudential choice model — the key to the rationing issues is to consider what it would be like to choose for oneself among different insurance polices that offer different packages of health benefits over a whole life-time. Such policies represent different allocations of benefits, and hence of resources needed to provide them over a life-time (President's Commission, Appendices, 1983b).

The other crucial feature of this model is that a person must choose ex ante — prior to being able to predict what one's own particular health prospects are. The reason for this restriction is obvious. If a man knows that he will or is likely to become chronically ill at 45, or if he knows that he is now 80 years old and that the incidence of serious illness among those his age is very high, he will choose a more comprehensive policy. Similarly, a woman who knows that she is at low risk for heart disease because of herself and at ~~low risk for~~ cancer because of her family history, will be prone to choose a less comprehensive policy and to spend the money saved on other goods. One vivid way to think of this is to envision disembodied persons about to be born — better yet, about to be conceived — who must choose a life-long insurance policy on the basis of general statistical information about the incidence and cost of disease for people in the society. The fact that the choice must be made ex ante makes it impossible for any one individual or group to tailor the choice to special needs.

The rational insurance or prudential choice model forces consideration of the opportunity costs of various alternative allocations of health care resources over a life-time (a person's own life-time). In deciding whether to have more resources spent early in life than later, a person is making a judgment about the value or quality of life — to the individual, not to others — during the time period in question. For example, someone might choose a policy that provides more prenatal and early childhood care than is currently available to many people in this country, and correspondingly less on coverage for aggressive intervention in the final stages of a terminal illness if that individual is over 75.

Similarly, a person might choose a policy that provided more supportive care — including home care that would permit maintenance of the individual's own residence and a more independent lifestyle when the person becomes old and disabled — instead of a policy that provided no supportive care but more extensive coverage for aggressive hospital care in old age, as Medicare currently does. In choosing a package of benefits, a rational individual would also weigh the benefits of spending more to extend life for a relatively short period of severe mental incapacity at the expense of greater coverage to prevent or cure life-threatening diseases, or to improve functioning and hence quality of life in earlier years, and vice versa.

The virtue of the prudential choice model, then, is that it offers a way of thinking about the tradeoffs represented by different allocations of a fixed amount of societal resources from a single perspective, without requiring or allowing one person's or group's peculiar perspective to determine what some other individual or group gets. It reconceptualizes what seemed to be an intractable problem of distributive justice as a problem of rational prudence.

The outcome of this approach may be a package of life-time benefits that relies in part on age or level of cognitive functioning as criterion of eligibility for certain health care benefits. It is important to emphasize that doing so does not imply that either age as such or level of cognitive functioning as such is a relevant factor in rationing. Instead, specific age or mental capacity "cutoffs points" for various benefits would function only as administrative criterion. The rational insurance shopper will choose a policy that employs a particular age, terminal illness, or some severity of mental incapacity as criterion for restriction on certain benefits only if these conditions are reliably correlated with such a significant reduction in the value of the services in question to the individual who satisfies those criteria that such restrictions are prudent. Severe dementia, for example, would be a legitimate criterion for exclusion from hemodialysis or coronary artery bypass surgery only if the extreme loss of cognitive capacity so reduced the quality of life for that individual that the resources in question would be better spent on other goods or services for that individual at some earlier time.

Thus the underlying basis of the allocation of benefits would be the overall value of this benefit package, as compared with alternative packages, to the individual. Consequently, it would be inaccurate to say that an allocation that included such criteria discriminates against the elderly or against the elderly severely demented, because to do so would be to overlook the crucial fact that the limitations on care imposed by these criteria fall equally on everyone over a lifetime. The fundamental idea is that of an individual making a long-term budget for him- or herself: What the person spends now will not be available later (and what the person saves to be used later cannot be used now). Thus the fact that some services will be curtailed when an individual is terminally ill or elderly and severely demented is no basis whatsoever for a charge of discrimination against the terminally ill, the elderly, or the severely demented.

The success of this approach to allocation choices that differently affect the old and the young and those with greater or lesser impairment of cognitive functioning depends upon the extent to which it is possible to determine what a rational insurance buyer would choose ex ante. If there is such radical disagreement among reasonable persons about the value of the alternatives under consideration that no determinate choice emerges from the model, then nothing is gained from it. It is not necessary, however, that the rational insurance approach be so powerful as to yield a single, uniquely correct answer to the question of allocation over a life-time. Progress will have been made if this device at least narrows the range of reasonable allocations by ruling out some as clearly unacceptable.

No doubt irreducible differences in basic values and attitudes toward risk will prevent the rational insurance approach from answering all important public policy questions. However, it seems evident that it can provide a broader consensus and achieve a narrower range of disagreement than would be possible if each member of a group chooses simply according to his or her own best interest as a member of that group.

The rational insurance approach is valuable not simply because if offers a way of excluding directly self-interested bias that leads to conflict over allocation policies. It also provides guidance in efforts to minimize distortions in judgment due to more subtle and indirect self-interest as well as misdirected benevolence based on inappropriate guilt. A geriatric specialist's explanation of why she and her colleagues expend great amounts of time and material resources on vegetative and severely demented patients illustrates what seems to be a widespread phenomenon: the disproportionate influence on treatment decisions (and hence on the allocation of resources) of motivational factors that are largely ethically irrelevant as a basis for sound decisionmaking (Howell, 1984).

> In our work, taking care of the body often stands as a metaphor for taking care of the whole person. Taking care of the body is the vehicle through which we express medical and nursing competence, respect for the person in our charge, and our own self-esteem.

The mixture of quite different motivations here is revealing. On the one hand, she indicates that taking care of the body of a patient — when only the body can be taken care of because the patient has virtually no cognitive function — expresses "respect for the person." It has already been noted, however, that respect for the person does not always, or even usually, require the prolongation of the mere physiologic life of the body. Second, care for the body is called a "vehicle" for satisfying interests of the providers that are quite independent of the well-being of the patient. The simile of a "vehicle" here suggests that patients are perhaps being used to bolster the professional self-image and self-esteem of the providers.

It is not hard to understand that those working with such patients should sometimes, perhaps often, have doubts about whether the services they are performing are valuable and appropriate expressions of their professional commitments. And the generally poor prognoses of these patients, as well as the patients' inability to show gratitude, can surely sap the providers' motivations. However, neither a misguided sense of respect for the patient nor the providers own interest in preserving self-esteem can ultimately stand scrutiny as legitimate reasons for lavishing scarce human and material resources on patients who do not benefit from them, or who benefit only very marginally — especially when those same resources could be used with much greater benefit for others or could have been used with greater benefit on these patients at an earlier point in their lives. It seems more than appropriate for persons who work in these extremely demanding and often depressing settings to explore alternative ways of maintaining their morale and self-esteem that do not hinder efforts to make treatment and allocation decisions on a more rational and ethically sound basis.

Some anecdotal evidence indicates that the willingness of families to sustain the lives of vegetative or severely demented and gravely ill individuals is disproportionately motivated by feelings of guilt. The following care illustrates this problem graphically (Michael Gilfix, personal communication)

> Mr. S was severely demented, showing no awareness at all of his surroundings, except perhaps for a few moments a day, and even in these brief periods of apparent consciousness he was totally uncommunicative and unable to recognize his family or to respond in any purposeful way to their words or affectionate touching. He was in the final stages of Alzheimer's disease, had suffered several serious strokes, and had metastatic cancer of the lungs. Mr. S's older daughter, who lived in the same town and who had always been very close to her father, agreed with the physician that aggressive treatment was no longer appropriate. However, a younger daughter, who had lived for many years in another part of the country and who had had infrequent contact with her father prior to the final stages of his illness, insisted in a long-distance telephone conversation that she was going to see that "everything possible was done for Dad." Her subsequent remarks, charged with deep emotion, indicated that she was attempting to atone for what she took to be her neglect of her parent over the years. She concluded by threatening to sue the physician and hospital if they allowed her father to die.

If this example is representative of widespread tendencies, then the cumulative effect of many such cases may be a serious distortion of decisions concerning care and treatment of some classes of incompetent elderly patients, with a corresponding misallocation of the resources needed for implementing those decisions. The rational insurance approach to the evaluation of social policy choices concerning allocation, when combined with a clear understanding of the appropriate Guidance Principles for individual decisions, as described earlier, can at least provide a check upon these tendencies by helping us to fix our attention on the appropriate ethical considerations.

Attempts to use the rational insurance approach as a guide to public policy in health care resource allocation must be tempered by an appreciation of two important points. First, the use of this procedure would be fair to the terminally ill or severely mentally incapacitated elderly only if the limitations on current medical benefits to them are actually compensated for by other benefits to them — benefits made available to them at earlier stages of life or currently in the form of nonmedical benefits such as supportive care. What this means is that any attempt to base a rationing policy on the rational insurance approach would be justifiable only if it included a "grandfather" clause to provide special exemptions for those who did not, when younger, receive those benefits that a rational insurer would choose ex ante in lieu of the benefits that are to be restricted later.

The practical implications of this point are considerable. For example, it would be quite unfair to use the rational insurance approach to justify restrictions on the provision of beneficial medical care to an elderly person who had already suffered from an unfair lack of access to care throughout his or her earlier life. This is especially true if the individual's poor health in old age is due in part to morally unjustifiable restrictions on access to care in earlier years.

The second point is more subtle. In determining whether to allocate more money to health care in earlier versus later years, to an extension of a person's period of normal cognitive functioning versus a prolongation of life once an individual has suffered a severe reduction of cognitive functioning, a person is estimating the value of life to him- or herself under these various conditions. But in making these estimates, it is essential not to let the evaluation of the quality of life as an elderly incapacitated individual be influenced unduly by defective current practices toward people who fall into this category. The evaluations must be made on the basis of the true potential for meaningful activity, relationships, and enjoyments (whether complex or simple), not on pessimistic or demeaning attitudes that some people now have toward that potential. The difficulty of avoiding such distortions is compounded by the fact that even the most objective current estimates of such an individual's potential for well-being may be influenced by deficiencies in the current pattern of resource allocation. For example, in the past the potential of Down's Syndrome individuals for productive activity, enjoyment, and meaningful relationships — and even their potential lifespan — was grossly underestimated. And because this misperception limited the care these persons received, it functioned as a self-fulfilling prophecy.

If the two preceding cautionary qualifications are adequately heeded, the rational insurance approach can serve as a useful heuristic for thinking about problems of societal resource allocation in health care, including those special and increasingly urgent problems that profoundly affect elderly, incompetent individuals. At the very least, this way of conceptualizing the rationing issue deserves further consideration by policy analysts and policy makers.

The Moral Responsibility of Families Towards Elderly Incompetent Individuals

As noted earlier, each of the Guidance Principles for making particular care or treatment decisions for incompetent individuals is exclusively patient-centered, and none of them makes any explicit reference to constraints on the use of scarce resources. Since non confers any positive right to services and the resources they require, the Guidance Principles must be understood as operating within a framework that specifies the scope and limits of morally justified legal entitlements to services. Yet it is highly probably that any system of legal entitlements to health care likely to exist in this country in the foreseeable future will be far from comprehensive, and that consequently families will be expected to bear a substantial share of the financial burden.

There are, however, limits on the burdens it is reasonable to expect family members to bear, and these limits must be kept in mind by the courts and protective agencies in their efforts to see that decisions concerning care and treatment are being appropriately made by family members. For example, even though the family ought to be guided by the patient's best interests (in cases in which there is no advance directive and Substituted Judgment cannot be exercised), the family has no moral or legal obligation to provide the very best care if doing so imposes excessive burdens on them or deprives them of resources needed to fulfill important obligations to other family members (such as their own children). For this reason, the fact that a family decides to place an elderly incapacitated parent in an adequate nursing home, rather than in the best facility money can buy, would itself not be a reasonable basis for guilt on their part, much less for justified intervention by the courts or protective agencies in the name of protecting the elderly person's rights.

Although there is no hard-and-fast general formula for determining when the burdens of caring for an incapacitated elderly family member become excessive, it does seem clear that the degree of responsibility is stronger or weaker depending upon the nature of the relationship, not simply its "closeness." In particular, it is plausible to hold that the obligation of grown offspring toward their aged parents are less extensive than those of parents toward their minor children or of spouses toward one another (Callahan, 1985). There are two main reasons for this. First, although children (usually) have benefited from their parents during the long period of dependency characteristic of human, they did not ask to be put in this relation of dependency. Instead, at least where effective and available birth control makes parenting substantially a voluntary matter, parents can reasonably be viewed as having assumed an obligation to care for their offspring until they are fit to care for themselves. Similarly, in the absence of premarital agreements to the contrary, a person voluntarily assumes special responsibilities for his or her spouse.

Children do owe special gratitude and support to parents who have chosen to make special sacrifices, those that go beyond what we think parents ordinarily owe their children. But because there was no mutual assumption of responsibility, children do not, as a matter of justice, owe their parents as much as parents owe their children or as much as spouses usually owe each other.

A second, perhaps less important reason for this conclusion is that although children have had no opportunity to make provisions for their own welfare, most normal adults have had the chance to make some provision for their own care during old age. The greater a parent's opportunity for doing so, the less the obligation of their offspring to incur serious financial burdens if the parent failed to take responsibility for him- or herself.

The conclusion that there are significant limitations on the obligations of people to their grown parents is especially significant because of the growing cost of long-term care and the increasing life expectancy of severely incapacitated elderly individuals. An interview in a recent television documentary on the problem of caring for elderly parents with Alzheimer's disease is illustrative (Frontline, 1985). An elderly woman — whose 88-year-old demented mother was in need of constant care and supervision 24 hours a day — complained bitterly that her entire adult life would be spent caring for others, with "no time" for herself. Her early and middle adult adult years had been spent as a mother, taking primary responsibility for raising her own children. Now her remaining active years would be devoted to caring for her severely demented but far from terminally ill mother. By the time her mother dies and she is free from the onerous responsibilities that rob her of friends and enjoyable activities, she will herself be old and incapacitated or in ill health.

This problem is becoming more common because modern medicine has become more successful in preserving the bodies of the very elderly than it has in preserving their minds. In the past, life expectancy was shorter, and terminal illness and severe loss of competence went more closely hand-in-hand — and fewer middle-aged and elderly people faced the prospect of years of caring for their elderly parents.

SUMMARY OF THE ETHICAL FRAMEWORK

The most fundamental principles constituting a theory of surrogate decisionmaking are the following:

- Ethical Value Principles, specifying the basic ethical values that are to be secured in dealings with incompetent individuals (these include respect for individual self-determination, concern for individual well-being, distributive justice, charity, and community);
- Guidance Principles, giving direction in deciding for incompetent individuals (these include the Advance Directive Principle, the Substituted Judgment Principle, and the Best Interest Principle);
- Authority Principles, specifying who is to decide for the incomptent individual; and
- Intervention Principles, specifying the conditions under which decisions are to be taken out of the hands of the surrogate decisionmaker.

Guidance Principles can conflict, and therefore priority rules for ordering them are needed. The appropriate ordering (and the one recommended by the President's Commission on Medical Ethics) is that in general a valid and clear advance directive should take precedence; if there is no advance directive, then substituted judgment should be applied; if this too is inappropriate, the Best Interest Principle should then be invoked.

The Advance Directive Principle states that the patient's clear and bona fide advance directive is to be followed. There are two types of advance directive (which may be combined): 1) an instructional advance directive (such as a living will) describes how the patient wishes to be treated under certain conditions, and 2) a proxy advance directive designates who is to make decisions for the incompetent.

At least in cases in which doing so would not be clearly contrary to the patient's most basic interests, an advance directive — like the contemporaneous choice of a competent patient — can provide a justification for withholding any form of life support, including feeding (by artificial means or otherwise).

There are several problems with an advance directive:

- The person who issued it may not have been competent, adequately informed, or free of coercive influences at the time;
- the document may be too ambiguous to provide adequate guidance;
- the person who issued it may not have thought clearly enough about his or her own values and goals;
- the person who issued it may not have recognized the inability of the designated surrogate to act as the person would have wished the surrogate to;
- therapeutic options might change between the time the advance directive is issued and the time the decisions need to be implemented;
- the person who issued it may have failed to appreciate the value of his or her own future life under greatly altered conditions; and
- some safeguards that can serve to prevent the competent patient from making imprudent decisions are not present in the case of advance directives.

Thus even if a competent person has the right to refuse life-sustaining treatment or care, it does not follow that the same choice always is to be respected if embodied in an advance directive. It may sometimes be appropriate to refuse to implement an advance directive when doing so would result in the death of an individual who, though incompetent, would with proper care and treatment lead a life that clearly contains more pleasure and enjoyment than suffering and pain. However, attempts to restrict the authority of advance directives run a serious risk of undercutting their value.

Advance directives are subject to the same limitations as the right of a competent patient to refuse medical care: They do not include a right to be killed, nor, alternatively, a right to receive whatever services a person wishes. In addition, an advance directive does not justify imposing significant health care risks on other parties.

The Substituted Judgment Principle states that a surrogate is to choose as the patient would choose if he or she were competent — extrapolating the decision from other closely analogous choices that patient made while competent or, more likely, from evidence about the person's preferences and general attitude toward life. Substituted judgment cannot be applied to an incompetent patient who never was competent or in situations in which there is insufficient or contradictory evidence of what the incompetent patient would want if competent.

An important limitation on the Substituted Judgment standard is that it may not be used to justify a course of action that serves the interest of others at the expense of the incompetent's basic interests. This limitation is justified both because evidence regarding preferences does not have the same moral weight as evidence concerning deliberate choices (as expressed in an advance directive), and because few safeguards exist for guaranteeing the accuracy of a family's claims about the incompetent patient's former preferences.

The Best Interest Principle states that a surrogate's is to choose what will best serve the patient's interests — i.e., that which would be of net benefit to the patient (taking into account the benefits and costs to the patient of each option). Intrapersonal quality-of-life considerations are indispensable for applying the Best Interest Principle.

Permanently unconscious patients are beyond the scope of the Best Interest Principle. Continuing to treat them is of no benefit to them — since they are totally and permanently unaware of themselves and their environment — and so life-sustaining care may be withdrawn. The Best Interest Principle requires only that these patients be maintained on such systems long enough to make a reliable prognosis that consciousness will not return.

For medical decisions, the appropriate presumption is that the family of the incompetent is to be the principal decisionmaker (except in emergencies where the family cannot be reached). "Family" is to be understood broadly as whomever the patient is most closely associated with. At least in the case of critical decisions, such as termination of life-sustaining care, a court-appointed guardian is in general the appropriate surrogate for an incompetent individual who lacks a family.

The presumption that the family is to serve as surrogate is challenged if any of the following conditions is satisfied: the family itself is incompetent to make the decision in question; the family member who is serving as surrogate is acting under duress; the surrogate has a conflict of interest that is likely to bias that person's judgment in ways that are contrary to the incompetent's important interests; there is evidence of previous neglect or abuse of the incompetent by the family; or the family is disregarding the incompetent's advance directive or, where substituted judgment is applicable, the family is acting in a way contrary to the incompetent's previous values and preferences.

Institutional Ethics Committees can perform several valuable functions in decisionmaking for incompetents.

- They can serve as a focus for bioethics education in the institution and the community.
- They can provide ethics consultation services for staff, patients, and family.

- They can serve as a forum for complaints about the surrogate's decisions by the health care team or others — sometimes achieving a satisfactory resolution of the conflicts without going to court.
- They can help revise and improve institutional policies and practices.
- They can improve the impartiality of the decisionmaking process by exposing biases and by calling into question unarticulated assumptions.
- They can act as a filter to determine which cases ought to be referred on to the courts or to government agencies.

Using advance directives and substituted judgment creates no new medical resource allocation issues peculiar to decisions concerning incompetent patients. Indeed, one of the predicted effects of their wider use would be to ease the strain on resources (by requesting the withholding of treatment and so removing both the moral reservations and fear of legal liability that often lead some physicians to "overtreat").

The rational insurance — or prudential choice — model is a valuable method for conceptualizing "rationing" issues as broadly understood. It offers a way of thinking about the tradeoffs represented by different allocations of a fixed amount of resources from a single perspective, without requiring or allowing one person's or group's peculiar perspective to determine what some other individual or group gets.

Allocations based on the rational insurance model that include age, terminal illness, or mental capacity criteria do not discriminate against the elderly or against the elderly severely demented, because the limitations on care imposed by these criteria fall equally on everyone over a lifetime.

Many allocational decisions now are made for morally irrelevant or inappropriate reasons, such as a family's guilt or a provider's interests in preserving self-esteem. The rational insurance approach to the evaluation of social policy choices concerning allocation can serve as a check on these tendencies by helping us to fix our attention on the appropriate ethical considerations.

Although the rational insurance approach cannot answer all important public policy questions concerning the rationing of resources, it at least can provide a broader consensus and achieve a narrower range of disagreement than would be possible if each member of a group chooses simply according to his or her own best interest as a member of that group.

The rational insurance approach is fair only if it includes a "grandfather" clause to provide special exemptions for those who did not, when younger, receive those benefits that a rational insurer would choose ex ante in lieu of the benefits that are to be restricted later. The rational insurance approach also must be based on objective estimates of quality of life under different conditions, undistorted by prejudice or the effects of defects in current allocation policies.

There are limits on the burdens a family can reasonable be expected to bear in caring for an incompetent elderly member. The family has no obligation to provide the very best care if doing so imposes excessive burdens on them or deprives them of resources needed to fulfill important obligations to other family members.

The degree of responsibility of one family member for another depends on the nature of the relationship. Obligations of grown offspring toward their aged parents are as such less extensive than those of parents toward their minor children or of spouses toward each other.

CHAPTER 4: CURRENT PRACTICES, LAW, AND INSTITUTIONAL ARRANGEMENTS: A CRITICAL ASSESSMENT

This chapter describes and explains in greater detail both formal and informal practices of decisionmaking for incompetent and questionably competent elderly people, and the institutional and legal framework within which these practices occur. Its purpose is not restricted to description and explanation, however. Current practices are evaluated by applying the analysis of competence set out in chapter 2 and the ethical framework developed in chapter 3.

HOW INCOMPETENCE IS DETERMINED, FORMALLY AND INFORMALLY, AND BY WHOM, IN VARIOUS SETTINGS

It must be emphasized that data are scarce here because comprehensive, empirical studies are presently lacking. It is generally agreed, however, that by far the majority of determinations of incompetence are made informally. In many cases, other people — spouses, family members, nursing home personnel, physicians, family attorneys, or neighbors — simply decide that an elderly person is no longer able to make his or her own medical decisions or to manage financial affairs, without any formal procedure and without any explicit declaration of incompetence being made, even to that person.

Even when the elderly person lodges no protest, it is not safe to conclude that the individual has freely delegated decisionmaking authority to others, or freely acquiesces in their implicit judgment that he or she is no longer competent. An 85-year-old widower who is almost entirely dependent upon his grown daughter for emotional support — and who lives with her because he is physically frail — will likely find it impossible to resist her efforts to take complete control of his assets. This financial dependence may itself contribute to a decline in his mental capacity, simply because it deprives him of opportunities to keep his faculties intact by exercising them, and leads to a lowering of self-esteem attended by depression.

Determining Competence to Make Medical Decisions

In chapter 2, it was noted that competency determinations in medical contexts are usually made without court involvement of any kind. This is not necessarily a failing, it was argued, because reliance on formal guardianship hearings is often unproductive and unnecessary. What is disturbing about this informality in the medical setting is not that competency determinations are made without court involvement, but that there is no assurance of consistency. There are often no clear and accepted criteria that: 1) articulate standards and operational criteria for such determinations, 2) fix responsibility on someone in the institution for establishing whether a given person is competent or incompetent to make certain decisions, 3) include effective safeguards against abuse or error, and 4) provide guidance as to when court involvement is appropriate.

The failure to develop and monitor compliance with policies that meet these minimal requirements can perhaps best be illustrated by focusing upon a growing body of evidence concerning the ways in which "No Code" orders ("Do Not Resuscitate" or DNR orders) are issued. Although it would be imprudent to make sweeping generalizations about other medical decisions based simply on DNR orders, the way in which an institution handles this one type of decision can provide something of a litmus test for other decisions. If an institution's practices concerning DNR decisions are seriously deficient, it is likely that it will not have sound policies for less highly visible and less dramatic types of decisions.

Perhaps the most shocking revelation of deficiencies was the so-called Purple Dot Affair, which came to light recently because of a lawsuit against a large hospital in New York State (State of New York, 1984). A patient went into cardiac arrest in his hospital room, during a visit by several members of his family. The resuscitation unit rushed into the room, but stopped short, then retreated, after one member of the team remarked that his patient was a "No Code." The outraged family, who apparently had not been consulted, demanded to know how this could be, since there was no DNR order in the patient's chart. It soon became known that a DNR order was marked in the patient's chart by affixing a purple dot to the chart, that nurses did this, and that purple dots were available in the hospital gift shop (where anyone could purchase them).

In another institution, instead of a purple dot, a red circle on the hospital room door next to the room number served as a secret code for "No Code" status — known only to hospital personnel, not patients or their families (Cranford, personal communication). The utter disregard for the rights of patients and families, and the enormous potential for gross abuses (namely, murder) that such "policies" carry are obvious.

It is to be hoped that such egregious deficiencies are rare. There is, however, mounting evidence that many, perhaps most, hospitals either lack an adequate DNR policy or have an announced policy with which few physicians comply. A 1984 study of three teaching hospitals that lacked any official DNR policy concluded that DNR orders are currently not fulfilling their major goals of promoting patient autonomy and facilitating decisionmaking prior to a crisis, where possible (Evans and Brody, 1985).

Another recent study at a large teaching hospital involved 82 private physicians, 75 residents, and 154 resuscitations (Bedell and Delbanco, 1984). This study indicated that only 19 percent of the patients had discussed resuscitation prior to its being administered, although 86 percent of the total group were competent. Further, only 33 percent of the families were consulted about whether resuscitation was to be used.

And although the vast majority of physicians — 151 out of 157 — said they believed in discussing resuscitation with patients, only 15 actually did so. In spite of this lack of communication, the physicians in 68 percent of the cases believed that they knew their patients' attitudes toward resuscitation; yet 8 out of 25 competent patients who survived resuscitation said they had not desired it. Moreover, the percentage of cases in which the physician discussed resuscitation with the patient did not vary significantly between competent and incompetent patients.

If this last study is representative, then many physicians and health care institutions fail grievously in two respects. They do not take seriously the crucial task of first determining whether the patient is competent to decide; then, if the patient is incompetent, they fail to proceed on the assumption that the family is to serve as surrogate (in the absence of evidence that they are not qualified to do so). Finally, it is important to emphasize that the hospital in question — unlike those in the first study — has for many years had an announced DNR policy that affirms the importance of patient and family participation.

The following case, reported by an experienced internist at a large university hospital, provides insight into why, in institutions that lack coherent policies, physicians often fail to make a careful determination of incompetence before identifying a surrogate and bypassing the patient as a decisionmaker altogether (Allen Buchanan, personal communication). The patient was terminally ill, suffering from cancer, with extensive metastases to the chest, abdomen, and brain. The disease was unresponsive to chemotherapy and radiation. The patient was brought to the hospital by her family, who said that she was confused and euphoric. The internist, who was primarily responsible for her care, did not interview the patient for purposes of evaluating her competence. Instead, he conferred privately with the patient's family, and recommended that a DNR order be entered in the chart and that no other aggressive treatment be undertaken. In retrospect, the physician says that he is confident that the decision to terminate treatment was correct, but he criticizes himself for not attempting to talk to the patient and determine if she was competent. He stated that he failed to do so because he found it psychologically easier to deal with the family than to confront the patient explicitly with the fact that nothing more could be done to retard the progress of her disease.

Still more basic issues regarding competence to make medical decisions in general, and decisions concerning resuscitation in particular, arise in the nursing home context, though the issues have received far less attention than the cases that occur in hospitals. Many nursing homes do not possess equipment for mechanical cardiopulmonary resuscitation (CPR); some do not call for paramedics to perform CPR, and they transfer patients to a hospital when they have a cardiac arrest. A director of a midwestern nursing home explained that at his facility, if during the nightly bedcheck it is discovered that a patient is not breathing, nothing will be done to resuscitate the individual (Allen Buchanan, personal communication). His explanation was that elderly people come to the nursing home to die, and that everyone was aware of that.

This policy is unacceptable for several reasons. First, not all residents of nursing home are old, much less old and so afflicted with illness that prolonging their lives through resuscitation never makes sense. Second, it would only be permissible to have such a blanket policy if it were clearly announced in advance of admission to all patients and their families, and if appropriate measures were taken to ensure that the patient when competent (or the appropriate surrogate when the patient is not competent) freely chooses to forgo this form of life support. Yet the director of the nursing home made it clear that the policy was announced at the time of admission (nor subsequently, for that matter), and that there was no procedure for ascertaining whether particular patients were competent to decide about resuscitation. Though such fundamentally flawed policies may not be common in nursing homes, they raise serious ethical concerns where they do occur.

This criticism of some existing practices does not rest on the erroneous assumption that CPR is appropriate for all patients, much less for all or even most elderly patients. In many cases, resuscitation is a traumatic and futile invasion to which an individual ought not be submitted. Although CPR has higher success rates for the exceptional cases of an otherwise healthy person who suffers cardiopulmonary arrest following survey or near-drowning, success is rare when CPR is used on the general hospital population, and rarer still in elderly patients with one or more serious chronic illnesses (President's Commission, 1983a). Nevertheless, broad statistical generalizations do not justify disregarding the preferences of a competent patient excluding the family from participating in the decisionmaking process when a patient is incompetent.

A policy for DNR orders is only one aspect of planning for crisis. Especially in the nursing home context, the same kinds of ethical considerations that speak in favor of issuring a "do not resuscitate" order may also in some cases justify a "do not hospitalize," or "do not feed by tube," or "do not administer antibiotics" order. Investing a surrogate with the authority to make these decisions is acceptable only within the framework of safeguards provided by a carefully thought-out and conscientiously monitored institutional policy.

Formal Determinations of Incompetence for Decisions Concerning Finances and Places of Residence

Again, although systematic data are scare, there is considerable anecdotal evidence of widespread confusion, error, and abuse in the procedures by which elderly individuals are determined to be incompetent to manage their own affairs and by which surrogate decisionmakers for them are identified. Two especially serious and apparently pervasive errors stem from a failure to appreciate two fundamental points: Incompetence is often intermittent, not permanent, and competence is decision-relative.

The first error is that a diagnosis is confused with a determination of competence, and the role of medical judgment in determining incompetence is thus misunderstood. For example, courts typically rely on affidavits from physicians in declaring an individual incompetent for purposes of appointing a guardian or conservator. In some cases, the affidavit will simply state that the individual is "incompetent" or "unable to manage his or her own affairs" due to "organic brain syndrome" or "cerebral arteriosclerosis." Aside from the fact that the diagnosis itself may be inaccurate, the diagnosis may be taken — by the physician and the judge — as entailing a global judgment of incompetence. This, however, is a mistake. A person may suffer from cerebral arteriosclerosis, from, Alzheimer's disease or other dementias, or from psychosis, and yet still be competent to make some decisions — at least at certain times in certain environments. As the President's Commission pointed out, the judgment that an individual is competent or incompetent to make a particular decision or group of decisions is not a medical judgment, but rather a judgment about the adequacy of the person's decisionmaking capabilities to the task at hand. As such, it cannot be reduced to a medical judgment concerning diagnosis (President's Commission, 1983a).

The second error lies in mistakenly believing that a determination of incompetence always justifies "plenary powers" for the court-appointed surrogate, even when the evidence of incapacity only supports a more limited role for the surrogate. A judicial finding of incompetence can result in a radical change in the individual's moral and legal status. There can be a total takeover by others, when in comer cases a more circumscribed sphere of decisionmaking authority for the surrogate would have provided adequate protection both for the incompetent and for those in whom the person's financial undertakings create legitimate expectations.

Both of these common failings are graphically illustrated by the "Dirty Sally" cases in California, which received a great deal of publicity a few years ago (Wadleigh, et al., 1979). Through a joint but highly uncoordinated effort of city officials and county administrators, an elderly woman who lived alone was deprived of her home, lost all her belongings and her pets, and was grossly deceived. This occurred even though the weight of evidence indicated that she was not in fact incompetent and posed no danger to herself or to others.

After complaints from her neighbors that her yard was filled with old furniture, and expressions of concern on their part that her house might be so unclean as to endanger her health, city officials first issued nuisance citations to "Dirty Sally." When this action proved largely ineffective, the matter was turned over to the office of the county public administrator (apparently in part out of fear that the public would react adversely to putting an elderly woman in jail for having a messy yard). A county worker arrived at the woman's house, told her she was just being taken for "a little ride," and delivered her to a nursing home instead. When she arrived at the nursing home — with only her purse and the clothes on her back — she was refused permission to use the telephone. Her house was sold, along with all of her personal possessions. One of her dogs was sold for experimentation, the other sent to the pound.

Nothing like a determination of competence occurred, and no effort was made to ensure that the intervention took the path of the least restrictive alternative, which would have limited surrogate decisionmaking to those areas in which it was necessary. Indeed, subsequent examination — after press coverage triggered a public outcry — revealed that the woman in question was healthy, that she regularly paid her bills, and that she appeared quite capable to managing her own affairs without significant risk to herself.

Apparently the only evidence of her incompetence — aside from her cluttered yard — was an affidavit supplied by the county and merely signed by her physician, which read as follows (Wadleigh, et al., 1979):

> In my opinion, the proposed conservatee is not able to manage her own affairs and is suffering from chronic brain syndrome associated with cerebral arteriosclerosis.

The affidavit also stated that the woman would not be able to attend the hearing in which her fate was to be decided "by reason of risk of increasing mental disability."

Granted the importance of being able to respond in person to those who wish to take control of a person's life, the right to appear at a guardianship or conservatorship hearing is a fundamental safeguard that ought to be waived for an individual by others only when there is strong evidence that exercising it would seriously endanger the individual's physical or mental well-being. In the "Dirty Sally" case, this basic right was disregarded in the most cavalier fashion, as the physician apparently signed the affidavit without investigating whether an appearance at a hearing would in fact endanger the woman's health. The physician late testified that he would not have singed the affidavit had he known that she was to be put in a nursing home.

This case also illustrates a third feature of "formal" determinations of incompetence in guardianship and conservatorship proceedings: the characteristic vagueness of the statutory definition of incompetence. Guardianship and conservatorship statutory definitions vary from State to State, but the most common definition of "incompetence" (something called "incapacity") is that a person is "unable to manage his own affairs," or "unable to care for himself" (Wadleigh, et al., 1979). The former is often illustrated by references to an ability to resist fraud or undue influence, as in the California Probate Code (Section 1801b). And the latter is often illustrated by references to health, food, clothing, or shelter (California Probate Code, Section 1801a). These standards, it must be acknowledged, represent a significant improvement over previous statutes, which included such characteristics as "old age" as indicative of incompetence.

However, this latest generation of criteria remains vague. It is crucial to understand that such definitions do not themselves indicate, much less constitute, clearly applicable and consistent standards for determining incompetence. At most they imply what is obvious — namely, that an individual who is totally unable to make decisions (e.g., the profoundly retarded, the comatose, the severely demented) is incompetent. But since, as indicated in chapter 2, decisionmaking abilities may be present to a greater or lesser extent, individuals may be more or less "unable" to care for themselves or manage their affairs. Consequently, a statutory definition of the common sort indicates nothing about how defective the ability to make decisions must be before an individual is considered incompetent. It is important to keep in mind that everyone's decisionmaking abilities — even those who are uncontroversially competent — are to some extent imperfect or defective (that is, no one is a perfectly rational decisionmaker in all contexts).

It is not difficult to see how these three conditions — the vagueness of statutory definitions, the failure to recognize the decision-relative nature of competence, and the confusion of a diagnosis of mental illness or neurological disease with a determination of incompetence — encourage the abuses or vividly illustrated by the "Dirty Sally" case. Nevertheless, it does not follow that the appropriate remedy is to try to specify more concretely the statutory definition of incompetence. Although a cautionary statement in the statute to the effect that a diagnosis of mental illness or neurological disease does not itself entail incompetence would be helpful, vagueness in the definition of incompetence seems unavoidable.

What is needed is a clearer statutory articulation of appropriate standards of incompetence, with emphasis on the factors examined in chapter 2. This would include, above all, reference to the complexity of information required for the particular decision and the risk involved. Greater clarity on the need for different standards for different decisions is not enough, however. More rigorous procedural safeguards than are presently available in many jurisdictions are needed as well. To help remedy these defects, procedures such as the following might be instituted in all jurisdictions where they are not already present:

- The subject of a guardianship or conservatorship hearing is notified of the hearing and of the right to appear.
- Hearings do not proceed without the presence of the individual whose competence is in question unless the individual has submitted a notorized statement waiving the right to appear, or there is well-documented, strong evidence from two or more independent medical or psychiatric experts either that the individual is unable to attend because of the potential of serious harm to him- or herself or that the individual attendance would be without meaning because of his or her level of incapacity. These statements by the physicians should be made under penalty of perjury and should include the last date on which the physician visited the patient.
- For all proposed wards or conservatees who are not represented by counsel, an independent investigation is to be conducted by trained professionals. The report resulting from this investigation — which would include personal, health care, and financial information — must be submitted to the decisionmaker and made available to all interested parties.
- Those who petition for a determination of incompetence bear the burden of proof that the least restrictive alternative is being taken (subject to appropriate resource constraints) and that the sphere of surrogate authority is as limited as is compatible with protecting the individual and the legitimate expectations of others.
- Reasonable efforts are made to restore or enhance competence where possible (e.g., through better medical treatment, nutrition, psychotherapy, or medication to relieve pseudodementia due to depression and other conditions that may be remedied).

- Evidence of lack of appropriate decisionmaking ability is provided from sources not likely to be biased by conflicts of interest. At the same time, corroborated evidence from those closest to the person is give due (though cautious) weight.
- Ongoing surrogate decisionmaking for financial management is supervised or reviewed periodically (by requiring, for instance, accounting reports from a conservator of the estate at regular intervals, at least where expenditures exceeding some specified level are involved).

These procedural safeguards are not offered here as definite requirements, but rather as a stimulus for further reflection. The specific form that such requirements take will of course be influenced by the particular provision of existing statutes, and these vary from state to state.

The need for embedding inherently vague definitions of incompetence in a framework of more rigorous safeguards is due in part to the reinforcing effect that pervasive attitudes have on tendencies to subordinate on elderly individual's interests to those who are his or her potential heirs. The following case demonstrates vividly how standards of decisionmaking ability are sometimes applied in an invidiously discriminatory way to elders, and in so doing promote the financial interests of relatives at the expense of the elderly person's autonomy.

The relatives of an elderly single man petitioned to have him declared incompetent on the grounds that he was making irrational financial decisions (Michael Gilfix, personal communication). It emerged that the gentleman's "irrationality" consisted of his propensity to send gifts to strangers who had done him some relatively minor service. For example, on more than one occasion he had sent roses to a telephone operator who had been especially helpful and courteous. Apparently, the man took great pleasure in such gallantries, and they were very important to him.

It is extremely doubtful that the issue of competence would ever have arisen had the individual in question not been elderly, with the prospect of leaving his assets to his relatives in the not-too-distant future. Here and in many other cases, behavior that in a younger person would at most be called quaint or somewhat eccentric (if not charming and generous) is branded irrational — in part because of the prejudice that equates being old with being mentally deficient.

Further, and perhaps more importantly, another erroneous assumption about the appropriate standard of decisionmaking capacity may be at work in this case — the tendency to impose on the elderly the standards for rational resource allocation that are generally appropriate for younger individuals, but that may in fact be irrational for the elderly. It is generally thought that the appropriate pattern of resource allocation decisions for a young or middle-aged adult as one that emphasizes a rather high ratio of savings to current consumption. This is, of course, quite reasonable, granted the crucial assumption that the individual has many years and many opportunities for enjoyment ahead. However, according to the standard economic model of rationality, what is rational for a young or middle-aged person may be irrational for an older one. In principle, perfectly rational elderly people might choose to spend their last penny as they draw their last breath.

It is a sad irony that in some cases the elderly are judged to be incompetent simply because they are behaving rationally. So long as the elderly individual does not squander his or her or resources in such a way as to become a financial burden on others or to renege on obligations to his or her family, the fact that the person's consumption pattern differs from that characteristic of younger rational individuals is no reason whatsoever for challenging competence.

The relative lack of due process and procedural safeguards that often characterize "formal" determinations of incompetence is especially striking when contrasted with the elaborate protections available in two other legal methods for curtailing an individual's basic civil and political rights: criminal prosecution and involuntary civil commitment proceedings. In the recent past, safeguards for involuntary civil commitment were often grossly deficient, but legal reforms and changes in attitudes toward "mental illness" have done much to improve the situation. On the face of it, it is somewhat puzzling that comparatively little attention has bee paid to the problems of error and abuse in guardianship and conservatorship, once it is recognized that the deprivation of freedom that results is sometimes almost as great as in criminal incarceration or internment in a mental hospital.

A standard explanation of the traditional lack of adequate safeguards in guardianship and conservatorship proceedings is that all involved have acted on the assumption that rigorous safeguards are not necessary because everything that is done is for the benefit of the alleged incompetent. The assumption of benevolent intentions, it is said, allows those in roles of authority — including judges and agents of public protective agencies — to view guardianship and conservatorship proceedings as essentially cooperative enterprises in which the adversarial approach (which is found in its most extreme form in criminal proceedings) is unnecessary. There are problems, however, both with the assumption itself, and with appealing to it as an explanation of current practices.

The assumption that rigorous safeguards are not needed because everything is directed toward the best interest of the alleged incompetent is too facile. As has been noted earlier, appeals to the needs to protect that individual are often nothing more than smokescreens for the conflicting interests of others, especially their financial interests. But perhaps almost as important is the fact that even genuinely benevolent intentions can lead to disastrous results when the would be benefactor is mistaken about what would be best for the individual the benefactor sincerely hopes to help.

Moreover, the "beneficent intentions" explanation does not fully explain why safeguards for involuntary civil commitments in general have recently been strengthened, while those for guardianship and conservatorship have not received as much attention — since it is generally assumed that a chief purpose of involuntary civil commitment is to protect (and, where possible, to benefit) the "mentally ill." It seems more likely that one reason that reforms in guardianship and conservatorship have lagged behind is that abuses are less publicly visible, more widely dispersed, and, in some cases, more subtle.

HOW SURROGATES ACTUALLY DECIDE FOR THOSE ELDERLY INDIVIDUALS WHO ARE CONSIDERED TO BE INCOMPETENT

Both the enormous diversity of types of decisions made by surrogates for elderly persons who are deemed incompetent and the current dearth of empirical studies of surrogate behavior make it impossible to offer systematic generalizations about how surrogates actually make decisions. This paper will have achieved a salutory result if it succeeds in calling attention to the need for further empirical research.

One area in which a picture of the behavior of surrogate decisionmakers has emerged is that of medical care, largely because decisions concerning the use of life-sustaining technologies are more novel and dramatic, and consequently tend to elicit more public attention than "merely financial" decisions. Information is also more likely to be available because of the institutional context in which medical decisions are made.

The data that do exist in this area suggest that health care professionals often fail to recognize and facilitate the family's presumptive roles as surrogate. First, there is direct evidence (presented earlier in this chapter) that physicians frequently make critical decisions — in particular, those concerning resuscitation — without significant participation by the family of the incompetent patient. Second, a number of studies of the behavior of physicians toward competent patients, as well as several recent court cases and the "Do Not Resuscitate" studies cited earlier, indicate that many physicians still behave as if the requirement of informed consent is a hollow legalistic ritual. Such physicians do not, in fact, adequately recognize the competent patient's right of self-determination. Indeed, the most careful and comprehensive study of informed consent now available states (Evans and Brody, 1985):

> It is not unduly harsh to conclude that current informed consent policy has been a dismal failure in the settings we studied, at least when measured against the loftier goals of the doctrine.

To a large extent, this disregard of the competent patient's rights is rooted in a paternalist attitude, according to which the physician is supposed to be the principal decisionaker (Buchanan, 1983; Gert and Culver, 1981). Indeed, the evidence suggests that physicians often take it upon themselves to act as surrogates for incompetent patients, even when family members are available and qualified to play that role.

Trends in Recent Case Law

Evolving case law also provides indications of how surrogates actually decide, though it would be naive to assume that compliance with the law is perfect. Current trends in case law are important not only because the perception about the legal permissibility of certain ways of making decisions can influence a surrogate's behavior, but also because new legal developments frequently serve as a kind of official recognition of the acceptability of practices that have already become widespread.

No attempt will be made here to expand the analysis already presented in chapter 3 to provide a comprehensive survey of recent legal doctrine as it affects the substance of surrogate decisionmaking. Instead, it will suffice to highlight what appear to be the most significant recent developments as they bear on the subject of this paper. Although the judicial rulings considered in the highly selective discussion that follows all involve decisions about medical care or treatment, their import is much broader. In part, this is because they rely upon the Guidance Principles set out in chapter 3, and these are so general as to cover the whole range of decisions, both medical and nonmedical.

Three developments in influential recent court rulings are especially significant:

- There is a growing recognition of the right of appropriate surrogate to refuse life-sustaining treatment or care for an incompetent, even in the absence of an advance directive authorizing refusal.
- Courts are rejecting the view that forgoing the use of sophisticated life-sustaining devices such as respirators is sometimes permissible but that withholding other procedures such as artificial feeding is never permissible. They are beginning to accept the fact that any sort of life-support may sometimes justifiably be withheld or withdrawn.
- Courts are showing an increasing awareness that Substituted Judgment is an appropriate Guidance Principle only for incompetents who previously were competent, not for all incompetents.

It is too early to say with confidence that each of these three elements will become firmly entrenched in the law in all or even in most jurisdictions.

Four recent rulings exhibit the growing recognition of the legal right of a surrogate to refuse treatment for an incompetent in the absence of an advance directive. The New Jersey Supreme Court's extremely influential 1976 ruling in In re Quinlan has received such wide attention that it is not necessary to present it in detail here (In re Quinlan, 1976). Quinlan affirmed the right of family members to serve as surrogates, and recognized their right to refuse life-prolonging treatment through the exercise of

Substituted Judgment in the absence of an advance directive. Perhaps just as importantly, this ruling also recognized that if such awesome decisionmaking authority is to be accorded the family, then the incompetent's interests must be protected by impartial institutional safeguards in the form of review of the family's decision by a "hospital ethics committee." The importance of this second element of the Quinlan ruling is that it marked the beginning of an attempt to develop new institutional arrangements to enhance the quality of decisionmaking. It represents an effort to remedy the defects of purely private decisionmaking without taking decisions out of the hands of those closest to the patient and turning the over to judges who are often ill equipped to make them.

In the more recent Brother Fox case, the New York Supreme Court also affirmed the right of a surrogate to request removal of a respirator as an exercise of Substituted Judgment (Eichner v. Dillon, 1980). The court accepted evidence from the patient's guardian and long-time friend that Brother Fox, an elderly Catholic priest who became permanently comatose after suffering a stroke during surgery to repair a hernia, had, when competent, clearly expressed a desire not to be sustained in such a condition.

In Severns v. Wilmington Medical Center (1980), the husband of a woman who became permanently comatose due to injuries received in an automobile accident petitioned to be appointed guardian of her person with authorization to request removal of "all medical supportive measures that were keeping [her] alive." Chancery Court granted the husband's request, and the Delaware Supreme Court upheld the ruling. Both courts affirmed that an appropriate surrogate (in this case, the spouse) can refuse life-sustaining measures through an exercise of Substituted Judgment.

In its decision, the Delaware Supreme Court interpreted "medical supportive measures" as including the use of a respirator, the administering of antibiotics to combat infection, and the surgical insertion of a feeding tube into the woman's trachea; it also stated that no order requiring cardiopulmonary resuscitation was to be written in the woman's chart. Although the husband had also explicity requested the removal of a nonsurgical inserted nasogastric feeding tube, the court omitted this form of nutrition from the list of "medical supportive measures." As noted in chapter 3, such a distinction between different methods of feeding is ethically arbitrary. In fact, the reasons the Delaware Supreme Court gave for allowing the withholding of a respirator and a surgically inserted feeding tube apply with equal force to the nasogastric tube as well, though the court failed to draw this implication. Although the language was not as clear as it might have been, the court held that "medical support" could be withheld if it held no reasonable prospect of providing benefit to the patient without disproportional benefit, if consistently applied, can also justify withholding forms of treatment of care that the Delaware court did not include under the rubric of "medical support."

The ruling by the New Jersey Supreme Court in the Conroy case also affirmed the principle that the surrogate can refuse life-sustaining measures for an incompetent patient, but it went further in two respects (In re Conroy, 1983). First, unlike Severns, Conroy did not distinguish between surgical and nonsurgical insertion of a feeding tube, and the court very forcefully held that there is no distinction to be drawn between withholding use of a respirator and withholding feeding by intravenous line or nasogastric tube. Although Conroy stopped short of explicitly affirming that any form of care, including "natural" feeding (by spoon), may also be withheld when doing so is required by Substituted Judgment or the Best Interest Principle, apparently this form of support was not at issue in the case (since the patient could not swallow, and so could not be fed in this way). Even more clearly than in Severns, the New Jersey Supreme Court's reasons for allowing withholding of "artificial" feeding support the withholding of natural feeding as well. Drawing on the report of the President's Commission, Deciding to Forgo Life-Sustaining Treatment, the New Jersey Supreme Court argued convincingly that the appropriate question is whether feeding, like any other life-support measure, accords with what the patient would want if competent or, where this is not or cannot be known, whether it provides for her a balance of benefits over burdens.

Conroy and another recent case, In re Storar (1980), both clearly affirm the limitations of Substituted Judgment as a Guidance Principle for surrogate decisionmaking. Reversing the error of the Massachusetts Supreme Judicial Court's earlier ruling in Saikewicz, Conroy and Storar, acknowledge that Substituted Jugdment is only applicable to individuals who previously were competent. Conroy does this by articulating a Best Interest standard for cases in which a decision cannot be based on the individual's previous values and preferences. The New York Supreme Court in Storar held that the question of what the individual would choose if competent has no sense when applied to a lifelong incompetent such as John Storar, who was profoundly retarded from birth.

According to the ethical analysis laid out in chapter 3, each of the three developments found i the court cases discussed here marks a significant advance in legal guidance for surrogate decisionmaking. Further progress is the law will require many more decisions, however. Rulings in one jurisdiction at most provide guidance but not precedents in other jurisdictions, and some issues have not yet been squarely joined by any higher courts. In particular, further refinements of the case law are needed to reinforce legal recognition of the fact that it is arbitrary to distinguish between respirator support and feeding (whether "natural" or "artificial") — in other words, that it is arbitrary to distinguish between technological and nontechnological forms of life support. Just as importantly, additional rulings will be needed to clarify the scope and limits of the authority conferred by advance directives and to interpret rapidly developing legislation designed to give advance directives legal effect.

ADVANCE DIRECTIVES AND OTHER PLANNING APPROACHES: WHO USES THEM, HOW EFFECTIVE ARE THEY, AND WHAT ARE THEIR PROSPECTS?

The phrase *advance directive* usually refers to living wills and durable powers of attorney, a convention that is followed in this paper. There, are, however, two other important, legally recognized instruments, by which a person, when competent, may exert control over decisions that are made after he or she becomes incompetent: a living trust and nomination of conservator. Although neither of these devices provides comprehensive control over future decisions, each is useful for limited purposes for some individuals.

Living (Intervivos) Trust

A Trust is a disarmingly simple concept. Once viewed as a preserve of the wealthy, millions of middle-income and older Americans in general are now taking advantage of its benefits.

A valid Trust is created by a written agreement in which a person, the "settlor," places some assets in the Trust for the benefit of him or herself or any other person. This latter person is called the "beneficiary." Someone must also be appointed as "trustee" to manage and control the assets.

Perhaps most typical is the Intervivos or Living Trust. Such a Trust is expressly revocable, which means that the settlor can modify or revoke the terms of the agreement so long as that person retains legal capacity. Thus the settlor retains control even after the Trust is created, so long as he or she is competent.

The settlor (or settlors — often husband or wife) may create a Trust for one or more reasons. The first, and probably most common, is to avoid probate. The probate process, by which a decedent's assets are passed along to heirs, is expensive and typically very time-consuming. By placing assets in a Living Trust, the settlor has created an alternative mechanism for passing along his or her estate. The Intervivos Trust also avoids conservatorship. In a typical Trust, the creators are the initial trustees. This means that they have complete, unrestricted control of their assets just as if they had not set up a Trust. In their Trust agreement, they also name "alternative trustees," who will take over management of the Trust in the event that the initial trustees — who may be the beneficiaries — become incapacitated. No conservatorship of the estate is needed because someone has complete legal control of the assets without recourse to the courts.

Another factor in setting up a Trust is that, unlike the probate process, it maintains the privacy of those involved. In the probate process, the will becomes something of a public document — barring special court orders, anyone can look at a probate file, which includes the decedent's will and listing of assets. Unwanted media attention sometimes results and, much more significantly, unscrupulous "con artists" have access to the names of the beneficiaries. Unlike the probate file, however, the Intervivos Trust is a private document. Uninvolved persons have no access to the Trust agreement, and therefore have no way of learning anything about the size or disposition of a deceased person's estate.

The Intervivos Trust also allows the settlor to monitor the performance of the trustee. By initially naming another person or entity (such as a bank trust department), the still competent settlor can evaluate the trustee's performance to decide if that particular trustee does an adequate job, and, if not, name another trustee instead. The Trust also can serve as a vehicle for minimizing inheritance taxes.

Finally, a Trust can be used to plan for such things as Medicaid eligibility. Although this subject is beyond the scope of this paper, there are numerous planning steps that can be taken to preserve a substantial portion of an older person's estate, particularly in the event of nursing home placement. The noninstitutionalized spouse thus need not become destitute before Medicaid will pay for nursing home and other medical care costs. The Intervivos Trust can provide an effective device for an elder — particularly one diagnosed as having Alzheimer's or Parkinson's disease, who may face nstitutional — to ensure that his or her care will not bankrupt the family.

Nomination of Conservatorship

The conservatorship usually is a court-ordered taking of independence and control from the elderly person — another person (or entity) is given control over the assets and/or person of the elder. Unlike an Intervivos Trust, the conservatorship is public in nature. Accountings (delineations of assets, income, and expenditures) must be filed, and are open to anyone's review. Although this may be viewed as an invasion of privacy, its purpose is to shield the elder from undue risk — without control of his or her own assets, the older person cannot be preyed on by con artists or unscrupulous business people.

Provisions for a conservatorship also may be made by an older person while still competent. The California Durable Power of Attorney for Heath Care Statute, examined in detail below, includes a place for nominating a conservator. A conservator may also be nominated in a very simple independent document or in a general durable power of attorney document (one not specifically limited to health care). Although a judge is not legally bound to honor such a nomination, it is unlikely that it would be disregarded without a weighty reason for doing so.

Notwithstanding its often intrusive nature, conservatorship plays an important role in protecting the elderly incompetent person. Although conservatorship by a person nominated in advance by the conservatee is not a substitute for the more extensive control possible with an Intervivos Trust or a Durable Power of Attorney, it provides somewhat greater scope for self-determination than when a conservator is appointed independently.

Living Wills

Two recurrent criticisms of living wills as advance directives have been that they are too general and vague to provide clear guidance on decisions to forgo life-sustaining treatment or care and that the documents themselves have no legal effect. Granted the difficulty of anticipating in detail every medical contingency, the former objection seems largely unanswerable. Natural Death Acts enacted in 26 States and the District of Columbia go part but not all of the way toward meeting the second objection.

For the most part, these statutes provide immunity — from criminal prosecution, from civil liability, and in some cases from professional disciplinary action — for health care providers who comply in good faith with a living will. However, like the California Natural Death Act (which in many cases served as a model), these statues do not impose civil or criminal penalties on a health care provider who refuses to comply. In some cases, the legislation states that is a physician cannot in good conscience comply, then he or she ought to facilitate transfer of the patient to the care of another physician (who will comply). But no civil or criminal liability is specified if they physician fails to do so.

In addition, some Natural Death Acts have duplicated a much criticized error of the California statute by counting as a "qualified patient" only an individual with a "terminal condition," defined as an incurable condition in which death is "imminent" regardless of whether life-sustaining procedures are used. The California law also added two other conditions for a valid living will: 1) the patient must wait 14 days after learning that his or her condition is terminal" before completing the living will, and, 2) the patient must be competent to sign the living will at the time he or she does so. The obvious catch her is that virtually no one will satisfy both these criteria: Few will be alive — much less competent — 14 days after it is determined that death is "imminent" regardless of what is done. Further, to restrict valid living wills in cases in which death is imminent regardless of whether vigorous support is given or not is to rob this form of advance directive of much of its value. The purpose of a living will is not simply to enable a person to ensure that undeniably futile measures will not be taken; it also, and perhaps mainly, is designed to ensure that care will not be provided that produces only minimal benefits in proportion to the burdens it involves, or that merely prolongs unconscious life.

Durable Power of Attorney

Dissatisfaction with living wills has led to greater interest in durable powers of attorney. Two kinds exist: general and limited explicitly to health care.

General Durable Power of Attorney

The general durable power of attorney is a document that a person, the "principal," signs in order to appoint another person or persons as "attorney in fact," with full or limited powers to act in the place of and on behalf of the principal. The general durable power of attorney an in principle be quite comprehensive, at least for financial matters. It can empower the attorney in fact to do everything that the principal could do with his or her assets: pay bill, apply for or disburse loans, sell or acquire property, and so on. Unlike the traditional power of attorney, this document is effective even if the principal is totally incapacitated and unable to make informed judgments.

The general durable power of attorney can be of two varieties. First, in the "springing" type, the power to act is not effective until the principal actually becomes incompetent. Thus the principal maintains control until he or she is no longer able to do so, and the attorney in fact cannot act before that time. A test (or set of criteria) for determining incompetence must be established and satisfied before this document will actually go into effect. The traditional and most common procedure is to have incompetence established by two physicians, including the principal's attending physician and, in some cases, an appropriate specialist. Although less formal and demanding criteria are sometimes used, they can be ambiguous and unreliable. This is particularly a problem when a dispute arises regarding an action taken by the attorney in fact. It might be objected, for instance, that the principal was not truly incompetent at the time the attorney in fact acted, and that the attorney in fact's power was therefore illegally exercised. This would render prior decisions invalid or, at minimum, questionable. Such a challenge to the attorney in fact's authority can have serious implications for third parties who rely on such documents.

The second type of general durable power of attorney becomes effective immediately and remains in effect after the principal is declared incompetent. This approach may be more appropriate for the elder who is already suffering from some degree of dementia (or some other form of physical or mental illness) because its force does not depend upon a finding of incompetence.

Durable Power of Attorney for Health Care

A general durable power of attorney can in principle be used to appoint a proxy for health care decisions as well as for nonmedical matters such as property management. However, reliance on a general durable power of attorney in health care matters does not provide the best protection for all concerned, at least where a durable power of attorney for health care is available. Use of the general kind is liable to be challenged on two counts: General durable powers of attorney were not specifically designed for health care decisions, and there is a widespread consensus that such decisions, especially those that are a matter of life and death, require special safeguards.

Forty States have general durable power of attorney statutes (President's Commission, 1983a). Pennsylvania and California have statutus that create a special durable power of attorney for health care, and it is very likely that other states will soon follow suit (Pennsylvania, Cons. Stat. 5601, 1982; California Stat. 1402, 1983). Because California's statute is much more carefully drawn and specific than Pennsylvania's, it will serve as the focus of this discussion.

The California Durable Power of Attorney for Health Care empowers a competent adult, using a rather uncomplicated printed form, to designate an agent (or "attorney in fact") to serve as his or her proxy for a broad range of health care decisions. Unlike a living will, it is not restricted to decisions concerning life-sustaining treatment or care. Five types of decisions are, however, explicitly excluded from the proxy's authority: commitment to or placement in a mental health treatment facility, electroconvulsive therapy, psychosurgery, sterilization, and abortion.

Aside from these specific exclusions, the proxy "may make health care decisions for you to the same extent you could make them for yourself. .. .were you competent to do so." This last statement is both reassuring and unsettling. As explained earlier in this paper, there is a broad consensus on the legal right of the competent person to refuse treatment, but here are still areas of disagreement. In particular, legal doctrine on the status of feeding (in various forms) as opposed to other life-sustaining measures (such as respirators) is at this point ambiguous, if not contradictory. The California Durable Power of Attorney for Health Care does not itself resolve — and should not be expected to resolve — the issue or whether a proxy may refuse feeding, or only certain methods of feeding, for an incompetent patient.

There is another unclarity in the California law concerning the forgoing of life support. Any "affirmative or deliberate act or omission to end life other than . . .to permit the natural process of dying" is explicitly forbidden (Lo and Steinbrook, 1984, p. 1600). The difficulty lies in the phrase, "the natural dying process," which suggests that there is one predetermined route, with death at its end point. But as many physicians have point out, for most patients in the final stages of a chronic terminal illness, there is almost always an opportunity to influence the time and manner of death by deliberate actions or omissions. What the law does not specify is whether refraining from administering antibiotics for pneumonia in a patient with metastatic cancer is "permitting the natural process of dying" or not. Here, as with attempts to draw moral distinctions between methods of feeding, the distinction between "natural" and "artificial" does nothing to resolve the basic moral issues. Using insulin to save a diabetic is "prolonging life by artificial means" and "interfering with the natural process of dying," but this does not make it wrong. The danger is that those physicians who tend to be overaggressive, or those who are unduly influenced by legal counsel whose sole concern is to reduce the probability of liability to zero, will respond to this ambiguity by giving it a very conservative interpretation. If this occurs, then the Durable Power of Attorney for Health Care, like the California Natural Death Act, will have achieved safety at the price of thwarting one of the mail purposes of advance directives: to allow people to ensure that their lives will not be prolonged under conditions they find unacceptable.

The possibility that the law's unclarity concerning life-support will lead to undue prolongation of life is heightened by the law's lack of adequate sanctions for a health care provider's compliance with the proxy's decisions. A health care provider is not made subject to criminal prosecution of civil liability or professional disciplinary action if he or she fails to "withdraw health care necessary to keep the principle alive" — even if the proxy refuses permission for such care, the patient would have refused it if competent, and a competent individual has the right to refuse it. Further, the law provides no penalty for a health are provider who, upon refusing such a request, does not facilitate transfer of patient care to another provider who will comply. Although the California statute's intention to protect the health care provider's right to conscientious refusal is laudable, this could have been achieved without undercutting the principal's right to delegate the right to refuse treatment of care.

A more balanced approach would be to impose civil liability on a provider who refuses to comply with the proxy's decision unless that provider takes on of two steps: transferring the patient to the care of a provider who is expected to comply (where one is available), or formally challenging the proxy's decisionmaking authority by seeking court intervention.

Another way to give the Durable Power of Attorney for Health Care teeth would be through the financial incentives of reimbursement mechanisms. Health care providers would be encouraged to comply with the proxy or transfer the patient by freeing the patient, the family, and the patient's insurance carrier from financial responsibility for the costs of all treatment and care that would not have been provided had the proxy's decision been honored.

The California law also lacks any provision for penalizing a proxy who disregards the instructions of the advanced directive. As with physician noncompliance, it is important to allow a proxy the opportunity to avoid doing something that he or she previously agreed to but that the proxy now finds unconscionable. However, respect for the proxy's values should not be allowed to vitiate the principal's instructions. To avoid this problem, a proxy who refuses to comply with the principal's instructions could be required by law either to relinquish authority to an alternate or to seek court appointment of a guardian (if the principal specified no alternate attorney in fact), or face civil liability.

Although a California Durable Power of Attorney for Health Care statute includes safeguards to ensure that the execution of the document is witnessed by parties who have no conflict of interest, there is one crucial procedural issue that it leaves unresolved. It does not provide guidelines for how, and by whom, the determination of the principal's incompetence is to be made. Since the statute does not require a formal adjudication of incompetence before the attorney in fact can begin to exercise his or her powers, it leaves the impression that this determination is to be informally — presumably with the physician and family playing a major role (Lo and Steinbrook, 1984).

The statute does implicitly acknowledge the decision-relative nature of competency by including the provision that even after the attorney in fact begins to exercise decisionmaking authority in some areas, the principal can independently accept or refuse treatment for which he or she is capable of giving informed consent. Nevertheless, safeguards are needed to ensure the integrity of the procedure by which the principal is declared to be incompetent (or incompetent for certain decisions). Perhaps most importantly, a strong case can be made for including in the law provisions to ensure that the testimony of the individual who is to serve as proxy is not allowed as evidence of the principal's incompetence. This simple procedural safeguard could help avoid the most obvious conflict of interest. Further, to minimize the possibility of collusion between the health care provider and the proxy, a determination of incompetence by an independent third party would also be appropriate.

It is to be hoped that adequate safeguards can be developed without the drastic step of requiring a judicial determination of incompetence in every of even most cases. Were this to occur, one of the main advantages of the durable power of attorney — avoidance of court intervention — would be undercut. Intrainstitutional guidelines requiring review of competence by an ethics committee, or documentation of an independent third party consultation on competence are plausible alternatives to both the unstructured approach tacitly encouraged by the California statute and the equally unattractive option of routine recourse to the courts. The purpose of the discussion here, however, is not to focus on any one particular proposal as uniquely correct, but rather to clarify a reasonable range of policy alternatives.

There are two remaining features of the California statute that deserve comment, and that legislators in other States would do well to consider carefully before drafting similar bills. The first has already been mentioned: the exclusion of certain types of decisions fro the proxy's sphere of authority. The exclusions were no doubt motivated by a recognition that there is a long and dismaying history of the abusive infliction of these procedures (e.g., sterilization, commitment to a mental hospital) on incompetence or allegedly incompetent people. Nevertheless, since various institutional and legal safeguards are now in effect that were previously lacking, it is necessary to face squarely both the costs as well as the benefits of such exclusionary safeguards.

One of the exclusions, electroconvulsive therapy, seems especially questionable. This treatment — which is highly successful with some individuals suffering from severe and debilitating depression — is now thought to be safer and less traumatic than many surgical or medical treatments that the proxy is allowed to authorize under the statute (including the use of highly toxic cancer drugs). If special safeguards are needed for certain procedures (such as electroconvulsive therapy), then a less extreme approach would be for the law explicitly to exclude them initially from the proxy's authority, but to allow the principal to sign a special authorization for any or all of them.

A second, perhaps even more questionable safeguard in the California statute is that the durable power of attorney dissolves whenever the principal revokes it, either in writing or orally — regardless of whether he or she is competent at the time of revocation. Further, the law states that the principal's refusal of any treatment or care always overrides the proxy's decision, again even if the principal is incompetent to make that decision.

Experience with demented patients suggests that this safeguard will in some cases render the durable power of attorney useless, thwarting the principal's efforts to delegate decisionmaking authority to a trusted person in the event of incompetence. Some demented patients, especially those suffering from Alzheimer's disease, exhibit periods of hostility and anger in which they may stubbornly refuse virtually any form of treatment or care, no matter how beneficial, and no matter how well it serves their lifelong values. To allow this kind of behavior to undercut the proxy's ability to make coherent decisions for the patient would not only thwart the principal's purpose; it also could disrupt the continuity of medical treatment and care. Again, a less debilitating safeguard is worth considering. Attempts by the principal to revoke a durable power of attorney, or determined protests against specific treatments, could trigger a documented reevaluation of competence by an independent party.

Yet another alternative would be to preserve the safeguards of the California law, but to include an option for the principal to sign a special "Ulysses Contract" stating that certain treatments are to be provided (or not provided) if the proxy chooses them, even if the principal at the time protests or attempts to revoke the durable power of attorney, so long as the principal is determined to be incompetent at that time. To assume, without argument, that such "self-binding" directives ought not be given statutory support is to exhibit a paternalistic bias (Howell, et al., 1982; Dresser, 1984; Elster, 1979).

Educational Efforts

The purpose of these critical remarks is not to denigrate the current legislation on advance directives. On the contrary, advance directives, and especially the durable power of attorney for health care, have a fundamental role to play in the development of more adequate arrangements for decisionmaking for elderly incompetent people. Carefully crafted legislation will not by itself suffice, however.

In addition there is a large educational task to be undertaken. In 1982, a survey conducted for the President's Commission on Medical Ethics revealed that only 8 percent of a sample of the general public had issued any type of written instructions indicating their preferences about medical treatment. Even in states with living will legislation, patients, their families, and even their physicians are unclear about the terms and procedures of living wills (President's Commission, MHCD Appendices, 1982). If anything, knowledge about proxy advance directives is probably even less widely disseminated. In spite of the educational efforts of many organizations — such as Concern for Dying, The Society for the Right to Die, the Hemlock Society, and the American Society for Law and Medicine — much more work remains to be done. It is particularly appropriate that medical societies and medical specialty groups should be in the forefront of the movement to educate the public — and their own memberships — about the opportunities for issuing advance directives.

Especially in the case of the durable power of attorney approach and the establishment of living trusts, most elderly people and their families will require legal counsel. The legal profession therefore has an equally important role to play both in educating the public and the medical profession and in ensuring that its own members are adequately informed about the rapidly changing law that governs advance directives. Furthermore, public policy as well as code of legal ethics should be revised, where needed, to acknowledge frankly that serious abuses can arise when an attorney represents the interests of the family rather than those of the incompetent elderly person (Gilfix, 1984). In cases in which the interests of the incompetent individual and those of the family are in conflict, it is unethical for the same attorney to represent both. As the use of durable powers of attorney increase, new fiduciary standards must be developed not only for the proxy and the health care provider, but also for lawyers and others who participate in what may be called the surrogate system.

SUMMARY OF CURRENT PRACTICES, LAW, AND INSTITUTIONAL ARRANGEMENTS

At present, most determinations of incompetence are made informally, by many different types of persons in different settings, including family members, physicians, attorneys, and nursing home personnel.

Although determinations of incompetence to make medical decisions need not routinely be accomplished through formal court proceedings, coherent institutional policies are needed within hospitals and nursing homes to ensure that incompetence is determined in an ethically and legally sound way. Such policies would:

- articulate standards and operational criteria for determining incompetence,
- fix responsibility on someone in the institution for establishing whether a given person is competent or incompetent to make certain decisions,
- Include effective safeguards against abuse or error, and
- provide guidance as to when court intervention is appropriate.

Recent studies of one critical type of medical decision — that concerning resuscitation — indicates that many, perhaps most health care institutions lack policies that satisfy these criteria or have policies but fail to comply with them.

Formal determinations of incompetence appear to be more frequent with respect to nonmedical decisionmaking, in particular concerning finance and placement in a nursing home.

There is considerable evidence of widespread confusion, error, and abuse in the "formal" legal procedures by which elderly individuals are determined to be imcompetent to manage their own affairs, and by which surrogates are designed for them. These defects in guardianship and conservatorship proceedings stem from several sources, including the confusion between a diagnosis (of neurological or mental illness) and a determination of incompetence, a tendency to overlook the decision-relative nature of competence and to accord the surrogate plenary powers where more limited authority would be adequate, and a failure to provide effective procedural safeguards to minimize distortions due to conflict of interest. To help remedy these defects, more effective procedural safeguards must be introduced into the guardianship and conservatorship process.

Adequate protection of the incompetent may require that ongoing surrogate decisionmaking for financial management be supervised or reviewed periodically.

Standards of competence applied to elders often reflect a bias against the elderly and inappropriately presuppose patterns of consumption that are reasonable for younger people but not for the elderly.

Case law concerning decisionmaking for elderly incompetent people is rapidly evolving. Most of the more influential recent cases involve medical decisions, but the principles they enunicate have a broader application. Recent court rulings exhibit three especially important developments, all of which are improvements, though they are not yet firmly established in all jurisdications:

- There is a growing recognition of the right of an appropriate surrogate to refuse life-prolonging treatment or care for an incompetent, even in the absence of an advance directive authorizing refusal.
- Courts are beginning to abandon the view that forgoing the use of sophisticated life-sustaining devices such as respirators is sometimes permissible but that withholding other procedures such as artificial feeding is never permissible; they are beginning to recognize that withholding feeding may sometimes be permissible as well.
- Courts are showing an increasing awareness that Substituted Judgment is an appropriate Guidance Principle only for incompetents who previously were competent, not for all incompetents.

At present, only a small minority of people execute advance directives.

Legislation to give legal effect to advance directives for health care is developing rapidly. The Durable Power of Attorney for Health Care provides hither to unavailable opportunities for comprehensive planning that can maximize an individual's control over his or her future and ease the burdens of those who will care for the person when incompetent. A central issue for those drafting new legislation concerning the Durable Power of Attorney for Health Care is whether additional provisions, such as the following, ought to be included:

- clear guidance for how incompetence is to be determined and by whom;
- effective penalties for health care providers and surrogates who refuse to follow valid advance directives — unless they seek court intervention for a determination of guardianship, or transfer care to another provider or an alternate designated surrogate who will comply; or
- an opportunity for the principal to sign a special form (a "Ulysses contract") waiving the exclusion of certain procedures (such as electroconvulsive therapy) from the proxy's authority and/or the right to revoke the durable power of attorney and to refuse treatments the surrogate chooses when the principal has become incompetent (an option that would be plausible only if special safeguards are provided, such as specifying that the principal's refusal to accept treatment or the principal's attempt to revoke the durable power of attorney may only be overridden if there is first an independent, well-documented

reevaluation that shows the patient to be clearly incompetent
at that time).

Living Trusts and nomination of conservator can be useful planning devices, especially when combined with the durable power of attorney.

The increasing use of advance directives in general, and of the durable power of attorney for health care in particular, necessitates the development of new ethical and legal standards for the fiduciary relationships these documents create. In particular, public policy and codes of legal ethics must recognize that attorneys may be subject to serious conflicts of interest, and the same attorney should not be allowed to represent both the incompetent individual and his or her surrogate.

A massive and diversified educational effort must be undertaken cooperatively — by medical and legal professional organizations, health care institutions, government and private organizations, legal scholars, and bioethicists — to inform health care professionals, lawyers, judges, and the general public about the specific problems of surrogate decisionmaking for the elderly, and about the institutional resources available for dealing with them.

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WITHHOLDING AND WITHDRAWING OF LIFE-SUSTAINING TREATMENT FOR ELDERLY INCOMPETENT PATIENTS: A REVIEW OF COURT DECISIONS AND LEGISLATIVE APPROACHES

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THE ROLE OF THE COURTS

Introduction

Some names we know not because of what they did, but because of how they died: Karen Ann Quinlan, Joseph Saikewicz, Brother Fox, Earle Spring, Claire Conroy, and William Bartling, to mention some of the most prominent. We know their names because there was conflict about how they would die, what medical interventions should be used to prolong their lives, who should make this decision, and on what basis. We know their names because representatives of these individuals — families, friends, physicians — went to court for guidance and protection in making these decisions. They felt obliged to seek court intervention because no statutes define the rights of individuals in their circumstances, and the courts have emerged as the primary public forum in which issues about medical intervention and the rights of patients have been debated for the past decade.

This paper was originally to deal exclusively with appellate court decisions regarding the withholding or withdrawing of life-sustaining treatment for elderly incompetent patients. The discussion was to be limited to three judicial areas: the general role of the courts in such decisions, the specific role of the courts in determining competence and protecting autonomy, and the role of the criminal law in such cases. This focus was chosen because the courts have created almost all the relevant law in this area by adjudicating individual cases on the basis of common law and constitutional law principles. Because of the complex nature of the issues, legislatures and regulatory agencies have remained relatively silent.

Traditional methods, like guardianships and durable powers of attorney, have been used in some instances, but usually without changing their original, much broader compass. More recently, adult protection services and public guardianship services have developed, but with a much broader agenda. The only type of legislation directly aimed at the withholding and withdrawing of life-sustaining treatment is "living will" legislation. Although drawn very narrowly to date, the debate on such legislation has helped to sensitize the public about these issues. To include these initiatives, the scope of this study was expanded to provide brief descriptions of traditional statutory mechanisms to protect elderly patients, and a detailed analysis of "living will" legislation.

The focus of this study remains appellate court decisions, since these courts are the only ones that create precedents. Nonetheless, some widely known and discussed trial court decisions, such as the case of Elizabeth Bouvia, are mentioned where they add to the analysis. A number of trial-level cases that have been reported in newspapers and journals are also included in the section on the criminal law system to help illustrate how that system actually works.

Although active euthanasia is technically illegal, the trial courts have used their discretion in sentencing to relieve many individuals of punishment for their acts. And in many of the cases, jurors, acting as the "conscience of the community," have actually absolved some defendants of guilt altogether. A discussion of these trial court decisions helps demonstrate that "the law" is much more than a rigid set of rules that are inflexibly applied. Rather, "the law" is a set of general rules that reflects societal policy and that is applied by prosecutors, judges, and juries in a way that reflects the values of the community. This is especially evident in the exercises of discretion in prosecutors' offices regarding who to prosecute in the first place, on the part of juries in deciding who to convict, and on the part of judges in determining appropriate sentences.

Why Cases Come to Court

In a society dedicated to fostering the ideal of equality and "equal protection under law," the courts serve to protect individuals from exploitation by others. In the area of withholding and withdrawing life-sustaining treatment, the courts generally have not been involved in retrospective punishment through criminal proceedings, but they have increasingly become involved in prospective decisions about treatment. These cases center on enforcing individual rights and establishing corresponding duties. Such cases have been presented to the courts for two primary reasons: Participants who have already agreed on a course of action want a guarantee of legal immunity before actually withdrawing or withholding medical treatment (e.g., Earle Spring, 1980), or appointment of a legal guardian is sought with specific authority over a treatment decision because of a dispute between family and providers over what course of action to take (e.g., In re Quinlan, 1976).

The role of the courts in each type of case is the same: to protect the rights of the incompetent individual about whose care others are making decisions, and to enforce the rights of competent patients to make their own decisions. The courts do this in a variety of ways, including (1) making the process public, (2) appointing individuals to represent the patient in court and in the health care setting, (3) using legal principles to decide cases, and (4) giving reasons for their decisions.

Definitional Problems

The President's Commission on Ethical Problems in Medicine recognized in 1983 that "phrases like 'right to die,' 'right to life,' 'death with dignity,' 'quality of life,' and 'euthanasia,' have been used in such conflicting ways that their meanings, if they ever were clear, have become hopelessly blurred" (President's Commission, 1983). This problem has been endemic in discussions concerning the treatment of the elderly patient.

The term "life-sustaining treatment," for example, is found in the title of this paper and used throughout it. It is not a term we are particularly happy with because of its vagueness. Courts and legislatures have used terms like "life prolonging," "life saving," and "terminally ill." When examined closely, these terms are not useful. What is the difference between "prolonging life" and "saving life"? If a life is extended for 5 minutes or 5 hours, or 5 days or 5 years, has it been "prolonged" or "saved"? Is someone terminally ill because he will imminently die of an identified disease? If someone has a disease that will lead to death in 10 years, is that person terminally ill? Should the rights of a person be dependent on whether the individual is called "terminally ill" or whether the treatment is deemed to be "life prolonging" as opposed to "life saving"? We have found all these terms useless in analyzing the rights of patients. We have chosen the term "life sustaining" reluctantly, although it is somewhat more emotionally neutral than the alternates. In this paper, "life-sustaining treatment" means any treatment that extends the length of a person's life, whether for a minute or for 50 years. It applies whether or not a person is "terminally ill" and whether or not the treatment is "life prolonging" or "life saving." Thus, while we are not particularly enamored of the term, we frankly could not think of a better one.

"Withholding" and "withdrawing" are clumsy words as well, but have the advantage of being descriptively accurate. More conceptually correct, but probably less intuitively clear, is the simple phrase "treatment refusal," which conveys the notion that all forms of treatment are being dealt with, and that the refusal is on the part of or on behalf of the patient. It is especially important to note that no distinction is being made between various forms of medical treatment on the basis of their utility, side effects, number of moving parts, novelty, expense, or other grounds. Such a distinction tends to be made on inherently arbitrary grounds, and to detract from focusing on the individual patient, and that person's rights and welfare.

Likewise, we do not think it is useful to distinguish among categories of adults (18 years of age or over) on the basis of age. Thus although this paper is concerned with elderly patients, it should be emphasized at the outset that the elderly have neither more nor fewer rights than the rest of the adult members of society. Hence, although a number of cases discussed here do not involve elderly patients, all of the principles derived from them are directly applicable to the elderly. The primary factor that compromises a person's right to refuse treatment is not age but incompetence, an issue dealt with in the second section of this paper. Definitional problems are dealt with in more detail in the section on legislative approaches.

The Right to Refuse Treatment

The Right of a Competent Adult to Refuse Treatment

General Rules. Individuals have a common law right to be free from nonconsensual bodily invasions. An unconsented-to invasion is a battery. As early as 1905 an Illinois court held (Pratt v. Davis, 1905):

> Under a free government at least, the free citizen's first and greatest right which underlies all others - the right to the inviolability of his person, in other words, his right to himself - is the subject of universal acquiescence, and this right necessarily forbids a physician...to violate without permission the bodily integrity of the patient by a major or capital operation.

More recently, courts have found that for the patient's consent to be valid, the physician must provide the patient with enough material information about the proposed procedure that the patient can give an "informed consent" (Canterbury v. Spence, 1972; Harnish v. Children's Hospital, 1982; Meisel, 1979).

In essence, the requirement that a physician obtain a patient's informed consent prior to performing a treatment is designed to ensure that the patient has some basic information prior to being asked to make a "go" or "no go" decision regarding treatment. The physician has specialized knowledge that is essential to making a reasoned decision, and the patient is the party who is to apply some of that knowledge to his or her own situation. The California Supreme Court explained this dyadic relationship as follows (Cobbs v. Grant, 1972):

> A medical doctor, being the expert, appreciates the risks inherent in the procedure he is prescribing, the risks of a decision not to undergo the treatment, and the probability to a successful outcome of the treatment. But once this information has been disclosed, that aspect of the doctor's expert function has been performed. The weighing of those risks against the individual fears and hopes of the patient is not an expert skill. Such evaluation and decision is a nonmedical judgment reserved to the patient alone. A patient alone should not be denied the opportunity to weigh the risks only where it is evident he cannot evaluate the data, as, for example, where there is an emergency or the patient is a child or incompetent (emphasis added).

Courts thus view a treatment decision not as a medical one, but rather as a personal decision by the individual who will be directly affected. It follows that if a person is empowered by law to decide to undergo medical treatment, he or she is also empowered to decline such treatment. If a person cannot decline treatment, the "right" to decide whether or not to undergo a treatment becomes a sham, equivalent to a "right to agree with your doctor."

In addition to the common law right to refuse treatment, some courts have recognized a fundamental constitutional right to refuse treatment. In the Karen Ann Quinlan case, for example, the New Jersey Supreme Court recognized that the right of privacy enunciated by the United States Supreme Court, "is broad enough to encompass a patient's decision to decline medical treatment under certain circumstances" (In re Quinlan 1976). That well-known case involved a young woman who was in a permanent coma and on a mechanical ventilator. The Massachusetts Supreme Judicial Court concurred in that holding in a case that involved Joseph Saikewicz, a 67-year-old severely retarded ward of the state who had cancer for which chemotherapy offered the only chance for a remission (Superintendent of Belchertown v. Saikewicz, 1977). Where the right to refuse treatment is seen as a fundamental constitutional right, a State's authority to abridge the right is very narrow, and must be based on demonstrating a "compelling state interest." Four potentially compelling state interests were mentioned by both the Quinlan and Saikewicz courts: protecting human life, preventing suicide, protecting innocent third parties, and protecting the integrity of the medical profession. In neither of these cases, however, were any of these state interests found sufficiently compelling to outweigh the right of the individual patient, as exercised by a proxy. The proxy could withhold chemotherapy (in the case of Joseph Saikewicz) or withdraw mechanical ventilation (in the case of Karen Ann Quinlan), interventions that could have prolonged their lives (Annas, 1979).

Life-sustaining Treatments. The right to refuse treatment is not limited to those patients for whom such a refusal would be of little or no significance. A close reading of the case law makes it apparent that competent adults who seriously express a desire to refuse treatment are permitted to do so, even when such a refusal would result in death.

The early cases in this area of the law almost invariably involved Jehovah's Witnesses who need blood transfusions in order to survive. The facts of the various cases indicate, however, that these situations are not about the forced treatment of competent patients. Perhaps the most famous and widely cited case is Application of the President and Directors of Georgetown College (1964). A 25-year-old mother of a 7-month-old child was brought to the hospital with a bleeding ulcer, having lost two-thirds of her blood. Both the patient and her husband were Jehovah's Witnesses, a religion that prohibits the injection of blood into the body. Exactly how this religious tenet is applied, however, is subject to interpretation. Thus, when the judge in this case spoke to the husband, the judge reported that "he advised me that on religious grounds he would not approve a blood transfusion for his wife. He said, however, that if the court ordered the transfusion, the responsibility was not his." The judge then went to the patient's room and noted that the woman was not in a mental condition to make a decision. The judge asked the patient if "she would oppose the blood transfusion if the court allowed it. She indicated, as best I could make out, that it would not then be her responsibility." The court was thus not dealing with a competent patient who opposed transfusions if ordered by a court, but rather with a patient who could not give her own consent to it. The court's decision cannot be construed as forcing blood on a patient who refuses it: The patient and her husband were relieved to place this responsibility on the court's shoulders.

Although a petition for a rehearing en banc was denied for technical reasons, a number of judges expressed the opinion that the single judge who decided this case had no authority to do so, and that, if he did have such authority, his decision was wrong. Circuit Judge (now Chief Justice) Burger asked in his opinion, "If the patient has objections to that treatment based on religious conviction, or if he rejects the medical opinion, are the courts empowered to decide for him?" He later answered this question by stating, "there are myriads of problems and troubles which judges are powerless to solve; and this is as it should be. Some matters of essentially private concern and others of enormous public concern are beyond the reach of judges."

Another so-called forced treatment case involved a 39-year-old father of two who had lost 60 to 65 percent of his red blood cells and refused to consent to a transfusion (United States v. George, 1965). According to the court, the patient was competent and rational. When the judge entered the hospital room, the first thing the patient said — before the judge asked any questions — was that he would not agree to the transfusion, but would in no way resist if the court ordered it. He maintained if the court ordered the transfusion it would be the court's will and not his; the responsibility for the act would be "on the court's conscience." The judge explained that he had no power to order the transfusion and the patient would be free to resist the transfusion by putting his hand over the site where the needle would be injected. The patient responded that he would in no way resist the transfusion once the judge signed the order.

These cases can be compared with one in which a 34-year-old father of two who was seriously injured refused necessary blood transfusions (In re Osbourne, 1972). The patient told the judge that if the court ordered him to be transfused, he would be deprived of "everlasting life." The patient said, "It is between me and Jehovah, not the courts....I'm willing to take my chances. My faith is that strong. I wish to live but with no blood transfusions. Now get that straight." No transfusion was ordered.

These examples illustrate that it is essential to distinguish between cases in which people truly refuse treatment, and those in which people refuse to affirmatively consent to treatment but are willing to voluntarily undergo or "assent" to treatment if ordered by a judge. Ordering treatment in the former case violates the individual's privacy rights, while in the latter case there is no such violation.

Unfortunately, much of our modern jurisprudence regarding the refusal of medical treatment is based on a misinterpretation of these and other early cases involving Jehovah's Witnesses. They were often initially decided in an emergency situation, in which adequate deliberation is necessarily precluded. They were unusual in the sense that the courts were dealing with patients who seem to have anomalously consented to very serious physical invasions, such as major surgery, but not to the much less serious intrusion of blood transfusions. The amount of invasion the court "orders" was therefore much less than the patient had already consented to. None of the patients affirmatively refused to have the transfusions, and many seem to have believed that their religion forbade consent to blood transfusions, but not transfusions ordered by the court. Finally, none of these early cases dealt with the constitutional right of privacy, which has played such an important role in the contemporary cases.

While Jehovah's Witness cases continue to come to court, more typical modern cases involve elderly patients who wish to refuse more invasive procedures on nonreligious grounds. An example is In re Quackenbush (1978). Quackenbush was a 72-year-old man who refused to have his gangrenous legs amputated. "His conversation did wander occasionally but to no greater extent than would be expected of a 72 year old man in his circumstances." He had shunned medical treatment over the past 40 years. He was neither terminally ill nor comatose. If he had the operations, he would live indefinitely, but not having the operations would lead to his death. The court in this case explicitly held that the State's interest in preservation of life is not sufficiently compelling to override Quackenbush's right of privacy to competently decide his own future "regardless of the absence of a dim prognosis." Other courts, like those in Massachusetts (Lane v. Candura, 1978) and California (Bartling v. Superior Court, 1984) have reached the same conclusion using similar reasoning, as discussed later.

Contemporary courts have indicated that for competent patients the finding of a "good prognosis" is insufficient to provide the state with the power to forcibly treat these individuals. Whether or not a prognosis is "good" is not a medical issue, and not an issue capable of being resolved by an objective test. Rather, a prognosis is good or bad based on a subjective evaluation of the facts of a situation. Thus, Quackenbush's life would have been extended if his legs had been amputated. Although this may seem like a "good" prognosis to physicians or judges, it did not seem so to Quackenbush. Seldom, if ever, is it proper for a State to force on a competent patient its view of a "good" prognosis. The right to refuse medical treatment is not conditioned on the State's finding, or not finding, that the proposed treatment is "good." Rather, it is based on the right of each citizen to make important personal health care decisions without interference by the State, in the absence of a demonstrable "compelling state interest."

Protecting the Rights of Incompetent Patients to Refuse Treatment

Substantive Principles. Of course, individuals cannot actually be self-determining after they become incompetent and lose their capacity for self-determination. Nonetheless, the proposition that an incompetent patient should be afforded the "right of self-determination" he or she could exercise if competent, insofar as possible, has been upheld by every court examining the issue since Quinlan. For example, the Massachusetts Supreme Judicial Court has strongly declared that the right to refuse treatment must extend to incompetent as well as competent patients "because the value of human dignity extends to both" (Superintendent of Belchertown v. Saikewicz, 1977). Courts could probably come to no other conclusion without seriously undermining the rights of the weakest members of society: the mentally incompetent who are unable to protect their own interests. It is critical to the protection of liberty for all of us that our basic rights continue to be respected after we are no longer able to protect them ourselves. As legal scholar Ronald Dworkin has argued (Dworkin, 1978):

> "The bulk of the law — that part which defines and implements social, economic and foreign policy — cannot be neutral. It must state, in its greatest part, the majority's view of the common good. The institution of rights is therefore crucial, because it represents the majority's promise to the minorities that their dignity and equality will be respected. When the divisions among the groups are most violent, then this gesture, if law is to work, must be most sincere . . . [taking rights seriously] is the one feature that distinguishes law from ordered brutality."

In this regard, the law protects the "dignity and equality" of incompetent patients by attempting to honor, in some measure, their right to self-determination. Since dignity and equality extend to all human beings, respect for the rights of self-determination cannot be limited by medical diagnosis (e.g., Alzheimer's disease) or medical prognosis (e.g., irreversibly comatose or vegetative) but should extend to all incompetent persons. The challenge is to devise a reasonable mechanism to discern what their wishes would be, if they could in fact exercise self-determination.

Since, by definition, an incompetent patient is unable to exercise his or her own self-determination by making decisions regarding treatment, this right must be exercised on behalf of the incompetent person by someone else if it is not to be forfeited. To avoid loss of this right, the surrogate should utilize the "substituted judgment" standard, i.e., the surrogate should make a good faith effort to make the treatment decision in the manner in which the patient, if competent, would make it provided there is sufficient evidence on which to base such a determination. As previously noted, the patient's choice concerning treatment is the primary relevant variable when dealing with a competent patient. To afford the incompetent the right to self-determination, therefore, the patient's previously expressed desires concerning treatment must be seen as the most critical factor in affording the now incompetent patient the right of choice, using other factors like lifestyle, values, and religious beliefs where relevant. The primacy of the "substituted judgment" test was recognized by the New Jersey Supreme Court in Quinlan, even in the absence of a clear declaration on Karen Quinlan's part, by granting the power to the "guardian and family of Karen to render their best judgment . . . as to whether she would exercise [her right to refuse treatment] in these circumstances" (In re Quinlan, 1976).

Preference for the substituted judgment test has been legally acknowledged by other courts dealing with the issue, and endorsed for both legal and ethical reasons by the President's Commission (President's Commission, 1983). In the Saikewicz case, for example, even though the patient had never made any decisions for himself, the court required a determination of the patient's own "actual interests and preferences" in ascertaining what decision the incompetent person himself would make if he could speak for himself (Belchertown v. Saikewicz, 1977:

> "The decision in cases such as this should be that which would be made by the incompetent person, if that person were competent, but taking into account the present and future incompetency of the individual as one of the factors which would necessarily enter into the decisionmaking process of the competent person."

The New York Court of Appeals, in the Brother Fox case, was able to avoid many troubling issues by focusing on the individual's right to make his own decision. Brother Fox, an 83-year-old member of the Society of Mary, who following routine hernia surgery was left in a permanent vegetative state on a mechanical ventilator, had previously expressed an oral desire not to be maintained by "extraordinary means" if he were ever in a situation like Karen Ann Quinlan. As the court noted, the issue of whether or not someone else can speak for the patient "is not presented in this case because here Brother Fox made the decision for himself before he became incompetent" (Matter of John Storar, 1981). Since, unlike the more casual statements of Karen Quinlan, Brother Fox's prior statements of desires were "obviously solemn pronouncements," the court ruled that they must be followed. As the New York court noted, prior declarations can provide "clear and convincing" evidence of a person's wishes, and in the absence of evidence to the contrary should be considered the best evidence to the declarant's actual preferences.

The President's Commission likewise argued that whenever possible "decisionmaking for incapacitated patients should be guided by the principle of substituted judgment" (President's Commission, 1983). The Commission argued that it was morally and legally necessary to respect a person's autonomy by permitting the person the ultimate authority to determine for him or herself the meaning of health and well-being. Since individuals frequently disagree on these concepts, the person with the greatest interest in how they are determined, i.e., the patient, should be afforded the right to have the final say when possible.

Although the substituted judgment test is indeed the primary and preferred test, in the absence of some competent prior expression by the patient, it is subject to abuse. The case of Mary Hier provides an example. When her case was first heard in court, Mary Hier was a 92-year-old woman who suffered senile dementia, thought she was the Queen of England, and had been institutionalized for more than 50 years. Based primarily on the fact that she pulled out her gastrostomy tube (through which she received all her nourishment because she was unable to take food orally), a lower court judge determined that she would reject such artificial feeding if she were competent to decide (In re Hier, 1984). Ironically, it is only by attributing competent motives to this act of an incompetent, aged, mentally ill nursing home patient that the courts could justify not replacing the gastrostomy tube. Indeed, the Appeals Court pictured her as a competent patient in agony (In re Hier, 1984):

> Mrs. Hier's repeated dislodgments of gastric tubes, her resistance to attempts to insert a nasogastric tube, and her opposition to surgery all may be seen as a plea for privacy and personal dignity by a 92 year old person who is seriously ill and for whom life has little left to offer.

As this example illustrates, with a patient who has never competently expressed a preference, "substituted judgment" can serve as a rationalization to mistreat or terminate treatment on patients who are undesirable or difficult in some way. Her guardian ad litem, Robert LeDeux, succeeded in returning the case to court and getting the court to order the gastrostomy tube replaced based on new evidence. Mary Hier is alive and well as of early 1986.

When it is not possible to ascertain the patient's choice or preference reasonably accurately (and this should always be the primary test used to protect autonomy), two avenues are open: Either adopt a rule that certain types of treatment can never be discontinued, or permit the discontinuance of treatment under certain clearly specified conditions. Courts have found the former rule too rigid and not protective of incompetent patients, since competent individuals can and do reject proposed treatments. The latter rule, however, requires careful articulation to prevent potential abuses. Under the parens patriae doctrine, the State requires that surrogates make decisions for incompetent individuals that serve the best interests of the incompetent. Cases in which the "best interests" test must be used include not only those in which previously competent adults have expressed a preference regarding treatment decisions, but also all cases of individuals who have never been competent to express such a preference: young children and the severely mentally retarded. The dangers of treating elderly patients using an "always treat" rule are well illustrated by the New York case of John Storar.

John Storar was a profoundly retarded 52-year-old resident of a state facility who had a mental age of about 18 months. His closest relative was his mother, a 77-year-old widow who lived near the facility and visited him almost daily. In July 1979, he was diagnosed as having cancer of the bladder, and his mother was appointed his legal guardian to consent to radiation therapy, which produced a remission. Internal bleeding began again in March 1980, and his bladder was cauterized in an unsuccessful attempt to stop the bleeding. In addition, the cancer metastasized to his lungs, and his condition were considered inoperable and terminal. Nonetheless, in May the physicians asked the mother for permission to administer blood transfusions. She reluctantly agreed, but in June asked that the transfusions, which were given every 2 weeks, be discontinued because of the distress they caused her son. Because the physicians believed Storar would eventually bleed to death without the transfusions, they sought a court order to do them, even though they agreed he had only 3 to 6 months to live because of the cancer. The trial court agreed with the mother on the basis that it thought she was in the best position to determine what her son would want. The New York Court of Appeals, unfortunately and we believe wrongly, reversed and ordered the blood transfusions continued (Matter of Storar, 1981).

The Storar court incorrectly determined that a medical treatment decision for a terminally ill adult mentally retarded person had to be made on the same basis as if the adult was a curable child who would live a normal life after a blood transfusion. Accordingly the court held that it was always in the incompetent patient's best interest to continue to receive blood transfusions even when the transfusions merely painfully prolonged the dying process for him. This analysis is manifestly incorrect since Storar was dying of cancer. The court very properly wanted to protect children and other incompetents from those who would deny them life-sustaining medical treatment for reasons other than the patient's best interests. But it failed to recognize that there may be times when such treatment only prolongs suffering and is therefore itself cruel, and it failed to suggest any test that parents, families, or trial courts can apply to decide if it is ever legally permissible to withhold life-sustaining treatment from this category of patients.

The "best interests" test arguably promotes self-determination since, in the absence of any idiosyncracy or a previous declaration to the contrary, it can be fairly assumed that patients will make decisions consistent with their own objective best interests. Specifically, it is an objective test based on a notion of what most reasonable individuals in society would be likely to do in the same or similar circumstances. For example, in Quinlan the court noted that a decision by Karen's parents to remove her from the respirator would be in her own best interests by using the following rationale: "This decision should be accepted by a society the overwhelming majority of whose members would, we think, in similar circumstances, exercise such a choice in the same for themselves or for those closest to them" (In re Quinlan, 1976). Of course, it can equally be argued that the core of the best interests test is aimed at protecting the patient's welfare, as objectively viewed by society as a whole.

But there are conceptual problems. In Conroy, for example (discussed later in this paper), the New Jersey Supreme Court attempted to articulate a hierarchy of "best interests" tests. Under the "limited objective test," life-sustaining treatment may be withdrawn if "there is some trustworthy evidence that the patient would have refused the treatment, and. . . it is clear that the burdens of the patient's continued life with the treatment outweigh the benefits of that life for him." Under the "pure objective test" (i.e., when there is no evidence about what the patient might want), "the net burdens of the patient's life with the treatment should clearly outweigh the benefits that the patient derives from life. . .[and] the recurring, unavoidable and severe pain of the patient's life with the treatment should be such that the effect of administering life-sustaining treatment would be inhumane" (In re Conroy, 1985).

As to the "limited test," if there is "some trustworthy evidence," it should be followed if sufficient, and ignored if insufficient. Seen in this light, it is simply another way of expressing the "substituted judgment" test. The "pure objective test," focusing exclusively on "recurring, unavoidable and severe pain" as the only basis for withholding or withdrawing treatment, is far too narrow. There may be other things, in addition to pain, like impossibility of recovery or the use of restraints, that objectively make continued treatment more burdensome than beneficial to the patient. The pure objective test tends to ignore the plight of the individual patient, by justifying actions that otherwise could not objectively be viewed as in their "best interests."

Procedural Mechanisms. Once the substantive principles are agreed upon (i.e., following the wishes of the patient if reasonably possible, and if these cannot be ascertained, then taking the action that is in the patient's "best interests"), what remains is developing a procedure that ascertains the patient's wishes or best interests accurately, fairly, efficiently, and in a manner that is societally acceptable (Cramton, 1972). Courts have become the primary forum in which both substantive and procedural guidelines are being debated and defined. The reason is not that courts are more intelligent than physicians, families, or other third parties. The reason is simply that judges (and not physicians, families, or others) have a social mandate to distill the values and morals of society on which most of these cases must ultimately be decided (Annas, 1979). In the words of Justice Benjamin N. Cardozo (Cardozo, 1921):

> "You may say that there is no assurance that judges will interpret the mores of their day more wisely and truly than other men. I am not disposed to deny this, but in my view it is quite beside the point. The point is rather that this power of interpretation must be lodged somewhere, and the custom of the constitution has lodged it in the judges. If they are to fulfill their function as judges, it could hardly be lodged elsewhere. Their conclusions must, indeed, be subject to constant testing and retesting, revision and readjustment; but if they act with conscience and intelligence, they ought to attain in their conclusions a fair average of truth and wisdom."

The mechanisms courts use to determine incompetency and patient preferences, appoint guardians, determine the authority of guardians, and grant legal immunity are explored in the next section.

Summary and Conclusions

Courts are open to those individuals (including health care providers and relative) who seek declaratory judgments concerning their rights and liabilities in treatment withholding and withdrawal situations prior to actually implementing the act. No court or legislature has ever required such prior review (In re Spring, 1980).

Courts generally appoint a guardian for the patient, and often an additional guardian *ad litem* to represent the patient during the legal proceedings themselves.

Once cases go to court, courts will decide them. Courts accept the testimony of medical consultants and of "ethics committees" in their deliberations, but have indicated that such evidence is likely to be conclusive only in "persistent vegetative state" cases at present.

Competent adults have the right to refuse any treatment, including life-sustaining treatment. This has been determined to be a common law right by all courts, and also a fundamental constitutional right by some contemporary courts. When seen as either, it can only be interfered with by the State (through court action) in cases where the State can demonstrate that it has a "compelling State interest" in interfering with the individual's exercise of his or her right to refuse treatment. The major potential State interests that courts have identified are protecting human life, preventing suicide, protecting innocent third parties, and protecting the ethical intergrity of the medical profession.

The preferred test used to determine the treatment should be given or withheld for incompetent patients is the "substituted judgment" test, provided reasonably probative evidence of the patient's preferences regarding treatment exists. Courts have generally found prior declarations of patients made while they were competent, including "living wills," to be the best evidence of the individual patient's preferences. In the absence of a prior declaration, courts have looked to the values of the patient and opinions of relatives and friends concerning the individual's likely preferences concerning treatment.

Where it is not possible to ascertain the patient's preferences reasonably accurately, courts have adopted the "best interests" test, which is viewed as an objective attempt to treat the person the way a reasonable person in the same situation would want to be treated. Attempts to further refine the "best interests" test have so far been unsuccessful.

The right to refuse treatment exists regardless of the nature of the disease, the age of the adult patient, or the status of the patient. The primary factor that limits the adult in the exercise of the right to refuse treatment is incompetence. The issue of incompetence is especially important to elderly patients, not just because they may suffer from a number of conditions that may actually compromise competence, but also because competent elderly individuals are often improperly determined to be incompetent.

THE ROLE OF COMPETENCE IN DECISIONS TO REFUSE LIFE-SUSTAINING TREATMENT

American law properly presumes that every competent adult is at liberty to consent to or refuse any proposed medical treatment or intervention. A further appropriate legal presumption is that all adults are competent, and the burden of proof is on those who would declare them incompetent. Accordingly, competence has become a central issue in all discussions of the "right to refuse treatment" (Annas & Densberger, 1984).

Unfortunately, as individuals age, the reality is that health care providers, family members, and others are more likely to conclude that actions that would not indicate incompetence at a younger age are more suspect in the elderly. This is not a new problem. Sophocles' sons brought a proceeding against him to obtain his property, and supported their argument that he was a lunatic on the basis of his preoccupation with writing his play, Oedipus at Colonus. In his defense, Sophocles read from the play, and asked the jury if it seemed the work of an imbecile. The jury reportedly applauded the reading, and declared Sophocles competent. One modern legal commentator opines that under contemporary statutes, use of this defense could result in the sons walking out of the courtroom "in control of his property" (Atkinson, 1979). Indeed, many states retain "advanced age" as sufficient grounds for appointment of a conservator over a person's property. It was only in 1976 in California and 1978 in Illinois that an individual could not be found incompetent merely because they were "old and sick" (Atkinson, 1979).

Society does not view all ages as having equal value, and generally holds the "demented aged in low esteem" (Cassell & Jameton, 1981). Physicians are likely to mirror this societal prejudice. For example, Earle Spring was a 77-year-old man in a nursing home with irreversible kidney disease and severe senile dementia. At a hearing to decide whether or not to discontinue his renal dialysis, his dialysis physician testified that in determining the appropriateness of continued dialysis treatment he considers "whether a person is a *real person*, whether the person is happy to be alive, *whether other people around him or her are happy to have him alive*" (In Matter of Earle Spring, 1980; emphasis added). We believe these loose and subjective quality-of-life standards to be clearly inappropriate. Even though the evidence of Spring's actual wishes regarding continuation of kidney dialysis was virtually nonexistent, the Massachusetts Supreme Judicial Court nonetheless affirmed a lower court decision that Spring would, "if competent, choose not to receive the life prolonging treatment." What really seemed to be at stake was the court's (and society's?) view that older people in Spring's condition, by virtue of their physical and mental limitations, do not have much to live for. The family testimony, for example, was to the effect that Spring had led a vigorous, active life, which *he* was no longer able to do. The fact, of course, is that it is almost always true that as people get older, their level of activity declines, and is often severely curtailed. It does not follow from this, however, that such a person would prefer to be dead.

Because of such prejudice, the aged may be treated not as competent adults, but as incompetent children. The medical view may often be that the aged are presumed incompetent to refuse medical treatment until they can demonstrate to a physician's satisfaction that they are competent.

In this context, a competence proceeding, and the subsequent appointment of a guardian, can be used as a weapon against the elderly. The results can be devastating. Reduced to the status of a child in the eyes of the law, "most statutes deprive the ward of the right to buy or sell property, to contract, to sue and be sued, to make gifts, to write checks, and generally to engage in financial transaction of any kind...of the right to vote, to marry, to operate a motor vehicle, and to consent to or refuse medical treatment" (Hortsman, 1975; Regan, 1981).

Because of the centrality of a competence determination to individual self-determination and well-being, it is critical that those assessing competence have a clear understanding of its legal meaning, and that the individual whose competence is being questioned be afforded due process of law. Due process, however, is meaningless if the concept of competence itself is not well understood and articulated. In this regard the courts have consistently utilized the notion of competence as a capacity to perform certain tasks, and have been willing to find individuals competent to perform some tasks (e.g., to decide where to live) while incompetent to perform others (e.g., to give a home or all of their belongings).

In the medical context, it will be concluded that the most reasonable way to conceptualize competence will be to ascertain the individual's capacity to understand and appreciate the information needed to give an informed consent or an informed refusal to the treatment under consideration. Thus capacity is proportioned to the seriousness of the decision, although what often seems to be at stake is the degree of certainty courts require concerning incapacity to perform a specific task. The less important the task in terms of its consequences to the individual, the more certainty is required for a finding that someone is incompetent to perform it.

Definition of Competence

Informed Consent and Competence

The informed consent doctrine requires that patients be given material information (information that might influence a patient's decision) about their conditions, proposed treatments (including the risks and benefits), and the alternatives (Annas, Glantz, and Katz, 1977 and 1981). Implemented in good faith by a physician, informed consent enhances both self-determination and rational decisionmaking. It is assumed that an informed patient has sufficient information on which to base a decision to accept or reject proposed treatment. Thus, it is important to assess the patient's capacity to understand and appreciate the information required to be disclosed so that those involved can be confident it is the patient's decision when he or she makes it.

Infants and comatose patients provide clear examples of patients who are incapable of making decisions regarding medical care. There are equally obvious cases where the patient is capable of making such decisions. Unfortunately, there are also many borderline cases from the perspective of the physician, who wants both to honor the patient's wishes (respect autonomy) and deliver good medical care (promote the patient's well-being), and at times these two objectives seem to conflict. There are, for example, cases in which the capacity of elderly patients to participate in the medical decisionmaking process appears questionable or where the physician believes that the patient's refusal is not reflective of that person's own values and preferences but is instead a product of psychological or sociological factors. Such cases are dealt with in a variety of ways with varying degrees of arbitrariness, including sincere attempts to objectively determine patient competence.

Approaches to Competence

A variety of approaches have been suggested to determine competence. The President's Commission on Ethical Problems in Medicine identified three: outcome, status, and function. Under the outcome approach, actual decisions by patients that do not reflect community values are used as evidence of incompetence. Under the status approach, an individual's competence is based solely on physical or mental status (i.e., consciousness, age, and mental or physical diagnosis). The functioning approach focuses on an individual's actual understanding and processes in decisionmaking situations (President's Commission, 1982).

Most commentators have assumed that the functioning approach is the correct one, and have tried to better define the attributes needed to function competently. One philosopher has suggested, for example, that any one of four increasingly strict standards can be required: (1) free action, which involves a voluntary and intentional choice; (2) authentic decision, which is a decision that reflects the individual's values; (3) effective deliberation, which is an evaluation of the specific alternatives and their consequences; and (4) moral reflection, which is, in addition to effective deliberation, reflection on and acceptance of the moral values upon which the decision is based (Miller, 1981). Two psychiatrists used an analogous classification of increasingly difficult tests and suggested the following four possible tests: (1) evidencing a choice; (2) evidencing an understanding of relevant issues; (3) rationally manipulating the relevant information; and (4) in addition to (2) and (3) appreciating the nature of the situation. In their words, "appreciation is distinct from factual understanding in that it requires the subject to consider the relevance to his immediate situation of those facts he has understood previously in the abstract" (Roth, Meisel and Lidz, 1977). The authors regard this as the "strictest" standard. It is also the most reasonable one and, if fairly applied, the one that is most appropriate in hospital and nursing home settings.

A "functioning" approach, incorporating the appreciation requirement, avoids the pitfalls of the second-guessing of an individual's personality that is implicit in the authentic decision and moral reflection test. The functioning approach also helps ensure that the decision the patient makes is one the person realizes will have consequences for him or her that are understood and found desirable or acceptable. In addition, the test has a solid legal pedigree in the context of treatment refusals.

The functioning test, including the appreciation requirement, is the one most often used by the courts, and was the key factor in two major cases of refusal of life-saving amputations by elderly patients. The cases were decided by appeals courts in Massachusetts and Tennessee about the same time, 1978, and did not refer to each other. The Massachusetts case involved Mrs. Candura, a 77-year-old widowed diabetic who was suffering from gangrene in her right foot and lower leg (Lane v. Candura, 1978). She had undergone two previous amputations (a toe and a portion of her right foot) and at the time of the second amputation, an arterial bypass had been performed in an attempt to decrease the probability of recurrences of gangrene. Her attending physicians recommended that the leg be amputated without delay. After some vacillation, she refused the operation and persisted in that refusal. The trial court held that Mrs. Candura was (Lane v. Candura, 1978):

> ". . . incapable of making a rational and competent choice to undergo or reject the proposed surgery to her right leg. To this extent her behavior is irrational. She has closed her mind to the entire issue to the extent that the court cannot conclude that her decision to reject further treatment is rational and informed."

The trial court concentrated on its finding that she had "closed her mind" and the court thus seemed to focus on "autonomy as effective deliberation." Ultimately, however, this appears to have been less important to the trial court than her actual decision, which the court characterized as "irrational," thus falling into the "outcome approach" trap. The appeals court, on the other hand, concentrated on her ability to "appreciate" her situation and its alternatives. The appeals court reversed the trial court's decision and stated that "Mrs. Candura's decision may be regarded by most as unfortunate, but on the record in this case it is not the uninformed decision of a person incapable of appreciating the nature and consequences of her act" (emphasis added).

The court noted that "until she changed her original decision and withdrew her consent to the amputation, her competence was not questioned." The doctors readily accepted her consent to the two initial amputations, and only questioned it when she disagreed with their judgment about her treatment. The court made it clear that competence is not to be judged by a standard of medical rationality, that is, what her physicians consider the only reasonable decision. Rather, the relevant factors were her understanding of the proposed operation and the consequences of refusing it. According to the court, "[Mrs. Candura] has made it clear that she does not wish to have the operation even though that decision will in all likelihood lead shortly to her death."

In an enlightening footnote, the court noted that one of the two psychiatrists who testified at the trial thought Candura was competent. Asked why he differed from the other psychiatrist, he replied, "I think it is just a personal philosophy type of thing where I believe persons ought to be given the benefit of the doubt as to what they want to do with their lives, whereas, Dr. Kelley, I guess, is more protective." The point is not which psychiatrist was "correct," but that they differed over the issue of the appropriate criteria for competence, based on their own "philosophical" views. It also points to the importance of physicians understanding and respecting the legal definition of competence. Because of the "philosophy" of a particular psychiatrist, Candura was deprived of her right to make her own decisions by the trial court. Obviously this type of testimony will not be very useful to a court or other decisionmaker charged with determining an individual's competence on the basis of the standard legal test.

The Tennessee case, involving Mary Northern, is similar, although in that situation the court found a 72-year-old woman incompetent to consent to or refuse amputation (Dept. Human Services v. Northern, 1978). As a result of frostbite, both of Mary Northern's feet were necrotic. They were coal black in color, "shriveled, rotting and stinking." According to the testimony, Northern was perfectly lucid and understood everything other than the condition of her feet. She believed her feet would heal without surgery, and refused to consider the possibility that she might die without the amputation. Because she would not explicitly acknowledge that she would rather die than have her feet amputated (she responded "possibly" when that question was put to her), the court determined that she was refusing to make a choice, and was "mentally incapable of comprehending the facts which constitute" the danger to her life. The court used the following definition to find her incompetent: "Capacity means mental ability to make a rational decision, which includes the ability to perceive, appreciate all relevant facts and to reach a rational judgment upon such facts."

The court did not adopt the "outcome test," i.e., it did not object to her refusal per se. Rather it was her capacity to make an informed decision that the court objected to: "On the subject of death and amputation of her feet, her comprehension is blocked, blinded or dimmed to the extent that she is incapable of recognizing facts which would be obvious to a person of normal perception" (emphasis added). The major fact Northern consistently was incapable of recognizing was that her feet were "dead, black, shriveled, rotting and stinking." As Judge Drowota wrote in a concurring opinion (Department of Human Services v. Northern, 1978):

> "If this Court could in good faith find that she perceived as facts that her feet do look and smell as they do, and that her doctors are telling her that she needs surgery to save her life, we would not interfere with whatever decision she made regardless of how much it conflicted with the substance of her medical advice or with what we ourselves might have chosen."

The judicial test of competence is based then on an individual's capacity to understand and appreciate the nature and consequences of his or her decisions. It can be restated in the medical care context by saying that if an individual understands and appreciates the information needed to give an informed consent, then that individual is competent to give both an informed consent and to refuse consent, assuming, of course, that the decision is made freely and voluntarily. The type and quantity of information that must be understood and appreciated will vary with the actual treatment options and with the risks and alternatives that face the patient, but not with the status of the patient (status test) or the actual decision made by the patient (outcome test).

Relationship of Competence to Other Factors

Physicians' use of the outcome approach, as in the Candura case, is probably the rule rather than the exception. Typically, competence is questioned only when a patient refuses to consent to a recommended treatment. Testimony before the President's Commission is consistent with this view: "Coherent adults are seldom said to lack capacity (except, perhaps, in the mental health context) when they acquiesce in the course of treatment recommended by their physician" (President's Commission, 1982).

Without a specific, consistent basis for questioning and determining competence, the patient's refusal, an easily identifiable target for criticism because it conflicts with the physician's view of the patient's well-being, can easily become a justification for paternalism. This may result in the substitution of the physician's own judgment and values for those of the patient, including the physician's conception of a "good" or "bad" decision. The physician may also attempt to establish a cause-effect relationship between some kind of mental or physical factor (e.g., depression or blood loss) and the decision to refuse treatment, thus enabling the physician to invalidate that decision on "medical" grounds and to proceed with his or her own decision.

A patient's age alone should never be a sufficient basis for a declaration of incompetence. But there are complicating factors. A patient may vacillate in a decision to accept or refuse treatment. This by itself does not constitute incompetence, but a patient who vacillates poses a problem to the physician attempting to discern what the patient wants. One sound approach is to incorporate in the competence assessment a reasonable waiting period for nonemergency cases, such as the case of an elderly person with a nonemergency medical condition, so that the patient's actual desires can be ascertained.

The difficulty in formulating policy for the vacillating patient lies in determining what constitutes a "reasonable period of time." If a question persists, treatment cannot be forced until a determination is made (either at the bedside or in court) that the patient is incompetent to make the decision regarding care in the specific instance. Treatment can continue, however, if the patient gives simple assent. This is because it is a much lesser harm to liberty to continue treatment to which the patient has at least assented than to force treatment against a person's will.

Another potential complicating factor is mental illness. The existence of mental illness does not always constitute incompetence, although it may. In one famous lower court decision, a 65-year-old schizophrenic woman, Ms. Yetter, refused surgery for breast cancer (In re Yetter, 1973). At the trial, she indicated that the operation would interfere with her genital system, affecting her ability to have babies, and would prohibit a movie career. Her caseworker testified, however, that based on conversations with her 6 months previously, at the time she refused surgery, she was informed, and she was "conscious of the consequences" of her refusal. The Judge concluded that although her refusal "may be irrational and foolish to an outside observer," and although it is now "accompanied by delusions," the delusions do not appear to be her primary reason for rejecting surgery. Accordingly, he upheld what he described as "her original understanding but irrational decision," on the basis that health care providers have an obligation to follow the competent and understanding wishes of their patients, even if their patients later become delusional or suffer other mental illnesses that bring their current competence into question.

On the other hand, the Northern case, discussed above, provides an example where a specific delusion will be sufficient to determine incompetence where the delusion concerns facts material to an informed decision (in that case, the inability to appreciate that her feet were necrotic, and that she would probably die if they were not amputated).

The limited amount of literature on treatment refusals has placed a heavy emphasis on the difficulties of dealing with a patient's "transient feelings of despair and hopelessness" and feelings of depression. Depression may often be a perfectly understandable and healthy response to catastrophic disease or injury. Moods affect the patient's decisionmaking capability, but do not necessarily render the patient completely incapable of making decisions regarding his or her care at all times.

Moods such as depression and anger are fairly common among patients who may be heavily medicated and away from their homes, in strange environments, and separated from their loved ones. Such separation and isolation is the condition of many elderly patients in nursing homes. Depression under such circumstances is understandable. Elderly patients in isolated nursing home situations are also likely to be devalued by physicians, and even some courts.

Seriously injured persons, such as those suffering spinal cord injuries or serious burns, may experience shock, grief, pain, depression, and adverse psychological effects from powerful drugs. Sometimes such feelings can be effectively treated with "supportive psychotherapy" or antidepressant drugs. If these treatments are indicated and not refused by the patient, it is certainly appropriate to pursue them. On the other hand, if the competent patient refuses such treatment and persists in a refusal of treatment, that refusal should be honored. The relevant question is whether a mood such as depression has become so severe as to undermine a patient's ability to understand and appreciate the nature and consequences of his or her decisions. If it has not, it alone does not justify a determination of incompetence.

Appointment of a Legal Guardian for an Incompetent Person

Legal guardians can only be appointed by courts, and the requirements for such appointment are set forth in State statutes. The state's power to grant authority over an individual to a guardian is part of its parens patriae authority (a term derived from the English common law concept of the King's role as father of the country). The notion is that the state will provide a "father" or guardian for incompetents, formally limited to "idiots" and "lunatics." At common law in England, a jury of 12 determined the mental status of an individual. "If an incompetent were determined by the jury to be a lunatic, the Chancellor committed him to the care of some friend, who received an allowance with which to care for him" (Hortsman, 1975). Modern statutes generally provide for a formal hearing before a judge, although the procedure can be expedited and completed in less than a few hours in an emergency medical situation in which a temporary guardian is appointed for the purpose of making a medical treatment decision.

Almost all of the most well known cases involving elderly patients in treatment refusal or withdrawal circumstances have involved the appointment of a legal guardian for the elderly person, who has been judicially declared incompetent. This has been the case, for example, in the Northern and Candura (although reversed on appeal) cases, as well as the cases of Earle Spring (77-year-old, withdrawal of kidney dialysis); Brother Fox (80-year-old comatose individual, withdrawal of ventilator); Claire Conroy (80-year-old severely demented individual, withdrawal of artificial nutrition); and Joseph Saikewicz

(67-year-old, refusal of chemotherapy for cancer). If incompetent persons must have guardians appointed for them to dispose of property, it certainly seems appropriate for guardians to be required for treatment decisions that pose serious risks to the individual or have life or death consequences.

The first major guardianship case did not involve an elderly person, although the age of Karen Quinlan was not a factor in the court's decision. Her father sought appointment as Karen's guardian for the purpose of ordering her mechanical ventilator removed. The hospital and physicians had informed him that they would not remove the ventilator. The lower court judge refused to appoint Mr. Quinlan the guardian, or to grant any guardian the authority to remove the ventilator. The New Jersey Supreme Court reversed, and awarded legal guardianship to Karen's father. It disagreed with the lower court that his closeness to Karen might cause him anguish and distort his "decisionmaking process." Instead the court held (In re Quinlan, 1976):

> ". . .while Mr. Quinlan feels a natural grief, and understandably sorrows because of the tragedy which has befallen his daughter, his strength of purpose and character far outweighs these sentiments and qualifies him eminently for guardianship of the person. . .of his daughter."

The court also noted that next of kin were statutorily preferred for guardianship, and there was "no valid reason" to negate this presumption in refusal of treatment cases.

Guardians have the legal authority to refuse all types of medical interventions when such refusal is based on what the ward would want (substituted judgment) or on best interests of the ward, when applying the substituted judgment test is not possible. On the other hand, in some jurisdictions, guardians may not have the authority to consent to certain types of treatment, like sterilization and use of psychotropic drugs, where conflicts of interest might exist.

In Massachusetts, for example, it has been determined that a guardian cannot consent to the forcible administration of antipsychotic drugs for either an outpatient (Guardianship of Richard Roe, 1981) or an inpatient (Rogers v. Commissioner of Mental Health, 1983). The courts based their rulings on the findings that antipsychotic medication has "devastating and often irreversible" side effects, that the treatment is extremely intrusive, and that guardians (such as parents) may have a conflict of interest because they derive benefit from the control of the patient's behavior. Because of these findings, these courts concluded that only courts, not guardians, could authorize the forcible use of antipsychotic medications.

Similarly, the New Jersey Supreme Court ruled in Grady that only a court, not a guardian, could authorize the sterilization of an incompetent (In the Matter of Lee Ann Grady, 1981). What these courts have done is to decide that certain procedures are either too risky, or so subject to abuse, or both, that courts must oversee their use. The impact of such cases on the treatment — withholding or withdrawing cases — is far from clear. The Grady case is interesting because it was decided by the Quinlan court. In Quinlan, the court specifically held that judicial intervention in treatment withdrawal cases was neither necessary nor desirable. It then decided Grady, a case that required court involvement to sterilize incompetent people. Following Grady the New Jersey court decided Conroy, which, like Quinlan, did not require court authorization to withhold treatment (although it did require the intervention of an ombudsman and court-appointed guardian).

Courts are willing and able to carve out exceptions to the rule that guardians are empowered to consent to (and therefore refuse) medical treatment for their wards. They have not chosen to do so in the general treatment withholding or withdrawing cases, but could do so in the future if abuses become apparent or conflicts of interest exist. In addition, there has been enough uncertainty concerning the guardian's authority to provoke considerable litigation. The Quinlan case is again the best example. After declaring Joseph Quinlan the guardian of his daughter, the court went on to explicitly spell out his authority regarding the termination of her mechanical ventilator, and with "full power to make decisions with regard to the identity of her treating physicians." Other courts have followed this general path: responding to a request for a judgment that both requests the appointment of a guardian, and asks for specific, judicially sanctioned authority to terminate treatment. Alternatively, legal guardians who have already been appointed for other reasons have petitioned the court for specific authority to order the removal of life-sustaining treatment.

For example, in the case of Mrs. Edna Marie Leach, a 70-year-old housewife with amyotrophic lateral sclerosis, her husband first sought guardianship (after Mrs. Leach's physician refused to honor his request to remove her from the ventilator), and then separately sought a court order as guardian to have all life-sustaining systems removed from his wife (and ward). The court granted the guardian's request, but only under certain conditions, and only after a hearing at which a separate guardian ad litem was appointed to argue on Mrs. Leach's behalf (Leach v. Akron General Medical Center, 1980). Likewise, in the case of Bertha Colyer, a 69-year-old heart attack victim who was resuscitated but who was left in a persistent vegetative state, her husband and legal guardian sought a court order to have her removed from the ventilator. In that case the Supreme Court of Washington held specifically that while a court always had to be involved in appointing a legal guardian, the statutory authority of such guardians in Washington "enables a guardian to use his best judgment and exercise, when appropriate, an incompetent's personal right to refuse life-sustaining treatment." The court made it clear that once the guardian was appointed, "the courts need not be involved in the substantive decision to refuse life-sustaining treatment" (Welfare of Colyer, 1983).

The Colyer court's statement can be fairly characterized as "the law." Specifically, only a court can appoint a legal guardian. However, once a legal guardian is appointed, that person can make the decision to order withdrawal of life-sustaining treatment on the basis of substituted judgment, or, if the ward's wishes are unknown, on the basis of the ward's best interests. With the exceptions of psychotropic drugs and sterilization, no court has held otherwise, and all courts that have ruled on the substantive issue of whether treatment may be withdrawn in a particular instance have done so upon the request of a physician, family member, legal guardian, or some other third party.

Whether or not a "legal guardian" must always be appointed to authorize the withholding or withdrawing of life-sustaining treatment from an incompetent person is a difficult question. There are some circumstances where the benefits from continued treatment are either nonexistent or so slight that some courts have indicated that appointment of a guardian is unnecessary if a close family member acts in the name of the patient. The issue has, however, only been directly discussed in three cases, all of which involved patients like Karen Ann Quinlan who were in (or nearly in) persistent vegetative states, and thus who had no reasonable possibility of regaining consciousness.

The first case is that of Mrs. Shirley Dinnerstein, in which the court was asked if prior approval of a court was necessary to write an order not to resuscitate a 67-year-old woman suffering from end-stage Alzheimer's disease and a variety of other disorders that left her confined to bed in an "essentially vegetative state" (Matter of Dinnerstein, 1978). The Massachusetts Appeals Court decided that when there was no real hope for the patient, treatment would be in her best interests only if there "was some reasonable expectation of effecting a permanent or temporary cure or relief from the illness or condition being treated . . .at the very least, a remission of symptoms enabling a return towards a normal, functioning, integrated existence" (emphasis added). Accordingly, the court concluded that the question of the do not resuscitate (DNR) order was "a question peculiarly within the competence of the medical profession of what measures are appropriate to ease the imminent passing of an irreversibly, terminally ill patient in light of the patient's history and condition and wishes of her family." In such a circumstance, i.e., where the critical question is the medical appropriateness of withholding specific treatment based on its potential to benefit the patient, neither guardian nor court approval was necessary.

The other two cases involved patients in permanent comas. In a Florida case, a terminally ill elderly gentleman, Francis Landy, had signed a "mercy will" prior to entering a "irreversible coma" and "essentially vegetative state" (JFK Memorial Hospital v. Bludworth, 1984). In addressing the specific question of whether under these circumstances the appointment of a guardian was necessary to exercise Landy's wishes under his "mercy will," the court held (JFK Memorial Hospital v. Bludworth, 1984):

> "The right of a patient, who is in an irreversibly comatose and essentially vegetative state to refuse extraordinary life-sustaining measures, may be exercised either by his or her close family members or by a guardian of the person of the patient appointed by the court."

Although the court insisted that judicial appointment of a legal guardian was not required, it did require that "at least two other physicians" certify that "the patient is in a permanent vegetative state."

In the third case, the Supreme Court of Washington was asked explicitly to reconsider its requirement in Colyer of a court-appointed guardian (Guardianship of Hamlin, 1984). The case involved a 42-year-old severely mentally retarded gentleman who as a result of pneumonia and hypoxemia suffered complete destruction of cerebral activity. He had no known relatives and was a ward of the State. Accordingly, appointment of a guardian was required. On the one hand, the court accepted the request that it reexamine its holding in Colyer, and modified it to conclude that in cases of persistent vegetative state diagnosis, "guardianship proceedings are [not] a necessary predicate to effective decision making." On the other hand, in the absence of a court-appointed guardian, unanimous agreement on the prognosis and treatment decision must be obtained from "the immediate family, the treating physicians, and the prognosis requirements would sufficiently protect against abuse and therefore eliminate the need for added judicial oversight through the guardianship procedure in this limited category of cases" (Guardianship of Hamlin, 1984).

These cases, and the vast majority of similar ones that never find their way into court, demonstrate that there is still considerable confusion regarding the necessity of a guardian in treatment withholding decisions. In the Earle Spring case, for example, the Massachusetts Supreme Judicial Court reviewed the history of guardianships in medical treatment decisions, and noted that in the past they had required "consent or its equivalent" (sometimes using consent of a spouse as "equivalent") for treatment decisions, and only turned to guardianships when "consent or its equivalent" was not available. The court also noted in passing the tradition of treating an unconsented-to treatment as "battery" and opined that it might be more useful to view this area of the law in terms of negligence (In the Matter of Earle Spring, 1980).

Although it is a battery to treat someone without their consent, it is certainly not a battery to refrain from treating (or to withhold or withdraw treatment). It would seem more reasonable to look at the withholding and withdrawing area as negligence. The critical issue is thus not consent (although "consent or its equivalent" might be required under certain circumstances), but negligence — i.e., is the treatment one that a reasonably prudent physician would not give under the circumstances. If so, it may be appropriate to withhold or withdraw such treatment without consent. For example, an incompetent patient could have a DNR order properly written without a guardian's consent, if resuscitation were not something a reasonably prudent physician would initiate under the circumstances. The next question is whether the guardian, if needed, must apply for specific authority to make medical treatment decisions.

This issue was first raised in the Quinlan case (and declared unnecessary), and raised again shortly thereafter in Massachusetts. The case involved a severely retarded 67-year-old man who was a ward of the state (Superintendent of Belchertown v. Saikewicz, 1977). He was diagnosed as having cancer, and chemotherapy was the recommended treatment. After a hearing, a probate judge decided that the patient, Saikewicz, would be better off without the treatment, and the Massachusetts Supreme Judicial Court (SJC) affirmed less than 2 months later. Two months later still, Saikewicz died. It was another 14 months after his death that the SJC released its now-famous opinion, which followed the Quinlan case in every major particular except one.

The SJC rejected the Quinlan court's delegation of immunity-granting authority to an "ethics committee," even in narrowly circumscribed persistent vegetative state cases. It held that if physicians and others wanted a grant of immunity before withdrawing life-sustaining treatment, such a grant could only be obtained from a court. Some commentators and some courts read this case to mean that all decisions by guardians to withdraw life-sustaining treatment must be approved in advance by a court of law. In part because of this misinterpretation of their holding, and in part because of subsequent confusion about it, the SJC clarified its ruling in 1980 in the case of Earle Spring, the 77-year-old nursing home resident with senile dementia whose family wanted him taken off of kidney dialysis (his son had been appointed temporary guardian) because they believed that is what he would want. On the specific issue of whether it was always necessary for a guardian to come to court for prior approval of such a decision, the SJC was clear: "Our opinions should not be taken to establish any requirement of prior judicial approval that would not otherwise exist" (In the Matter of Earle Spring, 1980).

The most recent case on guardianship authority is the New Jersey case of Claire Conroy (In re Conroy, 1985). This case is important not only because it is the most recent, but also because it is a carefully considered opinion by the same court that wrote the Quinlan decision. Unfortunately, it has served to make treatment withdrawal decisions by guardians for elderly incompetent persons, at least those who are in nursing homes, far more difficult in New Jersey. Indeed, almost a year after the decision, no treatments have been terminated on elderly patients in that State using the procedures defined in Conroy (Sullivan, 1985).

The case was brought by Conroy's only living relative, a nephew who had previously been appointed her legal guardian, who sought an order to have her nasogastric feeding tube removed after her attending physician refused this request. The New Jersey Supreme Court held that a legal guardian did have such authority without added court intervention, but only after a court had made a specific finding that the ward was incompetent to consent or withhold consent for the particular treatment in question. If such a determination has not been made, and "if the patient already has a general guardian, the court should determine whether that guardian is a suitable person to represent the patient with respect to the medical decision in question." This will involve a court examination of the guardian's knowledge, motivations, and possible conflicts of interest.

The court took special note of the New Jersey Ombudsman statute, which was designed to help protect the rights of the institutionalized elderly in the State. Its decision, which it limited to nursing home residents, requires the guardian to notify the office of the Ombudsman whenever action to terminate treatment is "contemplated." The Ombudsman is instructed to treat such a notification as a possible case of "abuse" and investigate it immediately. This investigation is to include the appointment of two physicians, in addition to the patient's attending physician, to examine the patient to confirm the medical condition and prognosis. If all involved, including the Ombudsman, agree that withdrawal would be what the ward would want in this circumstance, then the ward's wishes should be carried out.

If such a decision cannot be reached, then either of two best interests tests can be applied. Under the "limited objective test," life-sustaining treatment may be withdrawn if "there is some trustworthy evidence that the patient would have refused the treatment, and . . . it is clear that the burdens of the patient's continued life with the treatment outweigh the benefits of that life for him". Under the "pure objective test" (i.e., when there is no evidence about what the patient might want), "the net burdens of the patient's life with the treatment should clearly outweigh the benefits that the patient derives from life. . . [and] the recurring, unavoidable and severe pain of the patient's life with the treatment should be such that the effect of administering life-sustaining treatment would be inhumane." This very strict test, which centers on severe pain, is adopted because of the majority's belief that "when evidence of a person's wishes or physical or mental condition is equivocal, it is best to err, if at all, in favor of preserving life," and because not to adopt this conservative posture "would create an intolerable risk for socially isolated and defenseless people suffering from physical or mental handicaps." When either of these tests is used, the patient's family, including spouse, parents and children, "must concur in the decision to withhold or withdraw life-sustaining treatment." If all of these steps are taken "in good faith," then all actors have legal immunity for their actions.

There are a number of problems with this procedural approach. First, it seems wholly unnecessary where the patient has written an explicit living will and designated a proxy through a durable power of attorney. Secondly, as Justice Handler argued persuasively in dissent, the "pure objective test" that focuses exclusively on "recurring, unavoidable and severe pain" as the only basis for withholding or withdrawing treatment seems too narrow. There may be other negative considerations like probability of benefit, use of restraints, invasiveness, etc., in addition to pain that objectively may make continued treatment more burdensome than beneficial to the patient. Third, to require the Ombudsman to always assume the withdrawing or withholding of treatment is abusive until proved otherwise will likely discourage families and others from using this mechanism, even if doing so would fulfill the clear wishes of their nursing-home-bound relative. Fourth, although the court acknowledged that a major problem in nursing home care is finding a physician who will go there, it requires not one but three physicians to examine and report on the patient's condition. One outside consultant should suffice to confirm the medical condition and options. Finally, although many of the flaws in the Quinlan case have been clarified, the court continued to delegate its immunity-granting authority to third parties. In Quinlan, the delegation was to an "ethics committee" (which has been renamed a "prognosis committee"). In Conroy, the court delegated immunity-granting authority to a undesignated group that must concur, but need never meet: the guardian, attending physician, two consulting physicians, the Ombudsman, and, where either of the two best interests tests are used, the patient's family or next of kin.

These problems seem to flow from a too narrow reading of the facts. For example, pain was seen as a major issue by all parties, but there was conflicting evidence at the trial level about Conroy's pain. Pain is a major issue, but it should not be the only issue. The central issue is, as the court makes clear in most of its opinion, is the wishes of the patient, if they can be discerned, and if not, the patient's best interests.

Likewise, the attempt to narrow the opinion to encompass only nursing home patients is troubling and fatally flawed. It neglects the fact that all the relevant medical decisions regarding Claire Conroy were made not in the nursing home at all, but during her 4 months at the Clara Maas Hospital, where her nasogastric tube was inserted, removed, and reinserted, and where her guardian first requested that it be permanently removed. The dichotomy between nursing home and hospital is not only artificial and misleading in this case, it is artificial in the course of almost every elderly patient. Almost all will be transferred to hospitals when they require invasive treatment, and a large number of them will initially enter the nursing home via a hospital. The reasons provided by the court for the limitation to nursing homes suggest a procedure that might be different in degree, but not so extreme as to set one up different in kind. The five reasons given are the patients' average age; their lack of surviving parents, siblings, or children; the limited role of physicians in nursing homes; general understaffing and and the less urgent types of treatment decisions that are made in nursing homes. Of these, the patient's age, family status, and needed treatment are all unaffected by the physical setting.

This leaves the lack of physician contact and the general bad impression of nursing homes as justifying different kinds of procedures. Neither is sufficiently persuasive. Almost all previous nontreatment court cases have originated in hospitals, and this seems to be the setting in which patient wishes are most frequently ignored. There are more treatment decisions per patient per day made in hospitals, but the court gave no reason to assume that they are made so much better. By focusing on the nursing home setting, the court tended to ignore the plight of Claire Conroy, just as the Quinlan court wound up concentrating on physician liability and ignoring the interests of Karen Ann Quinlan herself (Annas, 1985). Because of this failure, and the extremely complex procedural mechanisms employed, the New Jersey solution is not likely to be a useful one for other States to follow.

Responsibility of Hospital and Physicians to Patient Who Refuses Life-Sustaining Treatment (including transfer)

The thrust of almost all the judicial decisions to date has been to prospectively grant legal immunity to physicians for following the wishes of competent patients or their legal guardians. In a few rare instances, however, physicians may refuse to honor the wishes of a competent patient. Traditional abandonment principles require physicians to find another physician to care for any such patients who require continued care (Annas, 1975).

Anticipating this problem, as noted above, the New Jersey Supreme Court in the Quinlan case explicitly gave Quinlan, as guardian, the legal authority to seek out other physicians for his daughter. Competent patients, of course, retain the right to hire and fire their individual physicians as well. But what if for some reason alternate physicians cannot be found? Is the competent patient's physician then at liberty to ignore the patient's wishes, or is the physician obligated to follow them even if following them is against his or her best medical judgment or conscience?

This difficult question was addressed directly in the case of William Bartling, a 70-year-old-man confined to an intensive care unit, and intubated with a mechanical ventilator, who asked that the ventilator be removed (Bartling v. Superior Court, 1984). His physicians, conceding that Bartling was competent, nonetheless refused to remove the ventilator because it would cause his death and they did not think this was a proper action for a physician to take. The hospital in which Bartling was residing, Glendale Adventist Hospital, aggressively opposed their patient, and went to court to argue against removal of the ventilator. Attempts by Bartling's lawyer to find other physicians for him were unsuccessful because of the publicity generated by the case.

A lower court refused to order the physicians to remove the ventilator. The day before the appeals court heard the case, William Bartling died, still in the hospital on the ventilator. Accordingly, the primary issue the appeals court had to address was the obligation of a physician and hospital to fulfill a patient's wishes when transfer was impossible. The court found that Bartling had a constitutionally guaranteed right to refuse treatment and that the strongest argument that the physicians and hospital could make was that the hospital, Glendale Adventist, was a "Christian, pro-life oriented hospital, the majority of whose doctors would view disconnecting a life-support system in a case such as this as inconsistent with the healing orientation of physicians." The court, while not doubting the sincerity of these ethical beliefs, was emphatic that in a conflict, the patient's interests are paramount and must control (Bartling v. Superior Court, 1984):

> "If the right to self-determination as to his own medical treatment is to have any meaning at all, it must be paramound to the interests of the patient's hospital and doctors. The right of a competent adult patient to refuse medical treatment is a constitutionally guaranteed right which must not be abridged."

Previous cases are in accord with this view (Superintendent of Belchertown v. Saikewicz, 1977; Satz v. Perlmutter, 1980). Indeed, the court went further, in a footnote, saying that if Bartling were still alive, it would have issued the following order (Bartling v. Superior Court, 1984) :

> ORDERED AND ADJUDGED that William Francis Bartling, in the exercise of his right of privacy, may remain in defendant hospital or leave said hospital free of the mechanical respirator now attached to his body and all defendants and their staffs are restrained from interfering with Mr. Bartling's decision.

A majority of States now have "living will" statutes that provide a mechanism for a patient to refuse treatment after he or she is no longer competent. Using a document called a "living will" or prior declaration, a patient can set forth his or her wishes concerning cessation or withdrawal of life-sustaining treatment after they become incompetent. In such cases it may happen that their attending physician disagrees with their decision, or refuses to carry it out for personal reasons of conscience. These statutes generally require the physician to transfer the patient to a physician who will carry out the terms of the declaration. Likewise, the Uniform Rights of the Terminally Ill Act, adopted by the National Conference of Commissioners on Uniform State Laws in August 1985, provides in Section 6, "an Attending physician or other health-care provider who is unwilling to comply with this Act shall as promptly as practicable take all reasonable steps to transfer care of the declarant to another physician or health-care provider." This Uniform Act and other living will statutes are discussed in the final section of this paper.

THE ROLE OF THE CRIMINAL LAW

This section deals with the role of criminal law in regulating the withdrawing or withholding of life-sustaining treatment from patients. Although the focus is on elderly patients, the age of the patient is not relevant to the general discussion of homicide and suicide. There are times when the age of the victim of an unlawful act is relevant. For example, child abuse can only be inflicted on children, and laws designed to protect the institutionalized elderly only protect that portion of the population. However, the law of homicide and suicide is not age-specific. Homicide laws are designed to protect all persons, regardless of age or physical condition. Therefore, although much of what follows does not deal specifically with elderly persons, all of it pertains to this special population.

The criminal law, in general, has not been used as a tool to regulate medical practice. Although criminal actions against medical professionals are not unknown, few such actions directly arise from the practice of medicine. Thus, a physician who is charged with Medicaid fraud, with sexually molesting patients, or with the prescription of drugs for nontherapeutic purposes has not been charged with a crime that involves scrutinizing the standard of care that physician uses in practicing medicine. By definition, for example, there is no medical standard for the nontherapeutic use of prescription drugs. A physician who provides drugs to a patient for recreational purposes is no different from a nonphysician who does the same thing. However, a physician who makes a good faith effort to treat a patient with unorthodox drugs or dosages, and is therefore using the drugs therapeutically, is unlikely to be charged with a crime, and even more unlikely to be convicted. The criminal law has simply not been used as a tool for regulating physicians' conduct when they are engaging in good faith efforts to treat patients.

There are a number of reasons for this. One is that the few courts that have confronted the issue have expressed enormous distaste for using the criminal law as a way to review whether or not a physician has properly practiced his or her profession. For example, in Commonwealth v. Edelin, the Commonwealth of Massachusetts indicted an obstetrician for manslaughter, arguing that he caused the death of a viable child in the course of performing an abortion. Although the jury found Edelin guilty, the conviction was reversed on numerous grounds by the State supreme court. One of the major issues in the case concerned the physician's determination that the fetus was nonviable. The court pointed out that even if his judgment was wrong, "manslaughter could not be supported by proof merely of a mistake in judgment, even if that was the result of negligence or gross negligence" (Commonwealth v. Edelin, 1976). All that was required of the physician was that his judgment be made in "good faith" and not be "grievously unreasonable by medical standards" (Commonwealth v. Edelin, 1976; emphasis added).

More to the point for purposes of this discussion, the court pointed out that there were "special factors" in this case. The first special factor had to do with the nature of the defendant. The court said:

> ". . . we deal here with the professional judgments of a qualified physician acting under stress at the operating table. . . . In the present case we have an attempted post hoc review of the attending physician's judgments through a battle of experts before a lay jury with a threat of criminal conviction and professional disgrace . . . . There should be caution and circumspection in the interpretation and application of a criminal statute which, as employed here, must necessarily trench on professional practice and constitutional freedoms. This implies a wariness in assessing the strength of a criminal case made against a physician before it is held that there is enough evidence to submit to a jury."

In a concurring opinion, three judges stated, "A larger teaching of this case may be that, whereas a physician is accountable to the criminal law even when performing professional tasks, any assessment of his responsibility should pay due regard to the unavoidable difficulties and dubieties of many professional judgments." This court makes clear beyond any doubt that in only the most extraordinary cases does it believe that the criminal law should be used as a way of reviewing physicians' actions when performing "professional tasks." The presumptions against criminality are very much in favor of the physician who acts in "good faith."

In addition to the courts' general displeasure at the use of criminal law, prosecutors also recognize both the undesirability and the difficulties of prosecuting physicians. One prosecutor for the Illinois state attorney has listed the following four problems that confront a prosecutor who wishes to prosecute the "rare case" against a physician who has withdrawn or withheld life-sustaining treatments (Ginex, 1982):

1) The attorney for the defendant physician, even in the most obvious case, will probably be able to find one or more physician experts who will testify that the defendant physician compiled with the medical standard of care;

2) The prosecutor must prove beyond a reasonable doubt that the patient's death was caused by the physician's act or omission;

3) The jury, especially where the wrongful act was committed for reasons of sympathy, is often reluctant to find physicians guilty of criminal acts the white collar crime problem mentioned

above; and

4) The accused physician or nurse may have acted according to the wishes of the patient or the immediate family.

In reading this section, one must keep in mind not just legal theory, but judicial and prosecutorial reticence when it come to prosecuting physicians.

Homicide

"Homicide is the killing of a human being by another human being" (Perkins, 1969). Not all homicides constitute murder. There is justifiable homicide, such as in self-defense or defense of another. Murder is a homicide "committed with malice aforethought." The word "malice" in this context does not mean ill will, spite, or hatred, as in ordinary conversation. Acting with the intent to kill constitutes malice absent some justification or excuse, such as self-defense. Additionally, to perform an act in "wanton and willful disregard of the obvious likelihood of causing death or great bodily injury is a malicious intent" (Perkins, 1969).

Manslaughter is unlawful homicide committed without malice aforethought (Perkins, 1969). Manslaughter can be voluntary, such as where one person kills another in a rage of passion, or involuntary, such as death resulting from gross negligence.

The common thread that ties these various forms of unlawful homicide together is that a wrongful or illegal act must be committed that causes the death of another person. Ordinarily, one must commit a positive act, such as poisoning, shooting, or stabbing, to commit a crime. A person cannot commit a crime by omitting to act, unless there is a legal (not moral) duty to act. Thus it is a crime to not file an income tax return, because there is a legal requirement to do so. As will be discussed in this section, whether a physician has a duty to act when he or she withdraws or withholds treatment is a key consideration in determining criminal liability. Killing someone out of a good motive, such as relieving pain, is not a defense to homicide. It is not the motive of the killer that is important, but rather the intent to kill that is the key element in unlawful homicide. Furthermore, the consent of the victim is not a defense against a charge of murder (Survey, 1973; Nesbitt, 1982).

LEGAL PERCEPTIONS AND MEDICAL DECISIONMAKING

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LEGAL PERCEPTIONS AND MEDICAL DECISIONMAKING

In March 1983, the President's Commission for the Study of Ethical Problems in Medicine and Biomedical and Behavioral Research (hereinafter referred to as President's Commission) transmitted to the President and Congress a report entitled Deciding to Forego Life-Sustaining Treatment: Ethical, Medical, and Legal Issues in Treatment Decisions. In his cover letter, Commission Chair Morris Abram stated (President's Commission, 1983):

> Although our study has done nothing to decrease our estimation of the importance of this subject to physicians, patients, and their families, we have concluded that the cases that involve true ethical difficulties are many fewer than commonly believed and that the perception of difficulties occurs primarily because of misunderstandings about the dictates of law and ethics. Neither criminal nor civil law precludes health care practitioners or their patients and relatives from reaching ethically and medically appropriate decisions about when to engage in or to forego efforts to sustain the lives of dying patients.

Nonetheless, misperceptions of the law persist, influence medical decisionmaking and action, and often have a negative impact on the care of dying patients, especially the elderly. Undue concern with imagined legal requirements and consequences may cause physicians to neglect or disvalue other, seriously significant factors that should figure prominently in the calculus of withholding or withdrawing life-sustaining treatment. Hence, this sort of approach is likely to yield neither an optimum decisionmaking process nor the "best" substantive decisions (Annas, 1981; Burt, 1981; Kapp, in press; Rothenberg, 1982).

This paper examines the influence of legal perceptions on medical decisionmaking, focusing on care concerned with life-sustaining technologies and the elderly. The extent of this influence, the accuracy of the medical community's legal perceptions, and reasons for misperceptions are discussed. Potential Federal policies for addressing this important topic are identified.

THE LAW/MEDICINE RELATIONSHIP

Traditionally, law and medicine have not had an antagonistic relationship. Rather, the relationship has been fundamentally a symbiotic, mutual, and cooperative one (Kapp, 1985b). In fact, the medical profession has aggressively co-opted the legal system over the years and used the law's authority to serve its own ends. Illustrations of this interaction include the medical profession's traditional power to determine for itself the standards of care to be applied in a malpractice action, the standards of information disclosure that constitute informed consent, and licensure/discipline standards for determining who is allowed to be part of the medical profession. The role of government in influencing such standards has historically been negligible.

Today, however, both attorneys (Kapp, 1985b) and physicians (Stone, 1985) perceive that the traditional symbiotic law/medicine relationship is under challenge, for a variety of reasons. The law is both a product of, and a contributor to, myriad other social forces that help to bring about the present tension.

First, authority in our society is no longer automatically accepted by everyone. There is a new-found expectation of, and demand for, the public accountability of professionals, both collectively and individually. The medical profession is no exception.

A second factor exerting pressure to reexamine and redefine the law/medicine relationship is the civil rights movement. Beginning with a narrow focus on racial justice, this movement succeeded in creating a mind-set that led to a more expansive generalization of rights. This notion of the value of personal rights spread eventually to health care, in terms of both broad "patients' rights" and particular, identifiable groups of health care consumers such as the handicapped or elderly. In the realm of health care, as elsewhere, people today have gone from marching in the streets to marching through the legislatures, administrative agencies, and courts.

Third, consumerism as a movement has progressed beyond Ralph Nader and specific cases to a more general rejection of unbridled professional dominance. The doctrine of caveat emptor has been substantially weakened, as witnessed by, for example, the proliferation of "second opinion" programs. The patient is now called a "client" or "consumer" and is no longer a passive part of a unilateral transaction. The physician/patient relationship today approaches more of an equal partnership.

Finally, government and public funds have become involved in the social financing of health care, especially in the last 20 years, through entitlement programs such as Medicare and Medicaid. This development has given the public an immediate financial stake, as well as an equally real but less tangible ethical interest, in the rights of patients within the health care system, in the access of persons to health care, and in societal control over the system's costs. This stake has compelled the legal system to become actively involved in surveillance of the quality of health care that is purchased with taxpayers' dollars.

Until relatively recently, the main focus of medicine in the United States was on the control and cure of acute, episodic medical problems, such as infectious diseases. Most patients got sick, were treated, and either got better or died quickly. Today, concern for acute medical problems, such as heart attacks or traumatic injuries, is still an important component of medical care. However, advances in medical technology and the aging of the population (a related trend) are slowly shifting some of the emphasis in contemporary medicine from acute to chronic, long-term problems and their care. Many patients now have significant medical difficulties (such as hypertension or other heart disease, cancer, or pulmonary disease) that persist and require medical attention over a long period of time. The medical profession is still learning how to expand from an exclusively acute orientation to include a concern for chronic disabilities as well.

In addition, several age-related illnesses (e.g., Alzheimer's disease and other forms of dementia) diminish mental capacity. These deficits often make medical decisionmaking more difficult and strain further the medicine/law relationship.

A related phenomeon is the advent of "halfway" technology. Technologies have been developed that can keep alive certain patients who previously would have succumbed, but that often are not capable of curing these individuals or restoring them to normal functional status. Ventilators, artificial means of feeding, and sophisticated antibiotics are well-known examples. The result is a sizable number of patients who exist in a status of mental and physical "limbo," neither dead, on one hand, nor healthy and able to participate fully in life, on the other hand. Although this phenomenon is not age-related per se, many of the patients who occupy this middle status are elderly.

Nonetheless, as technological developments have occurred and become publicized, the demand for the use of such life-sustaining technologies has grown among physicians and the public alike. One explanation for the popularity of "high-tech" medicine is the "technological imperative," the (often unconscious) philosophy that simply because a particular technology exists, it must be used. Put differently, there is a reluctance to permit technology that has been developed at great cost and effort to ever sit idle. Another explanation is that it is impossible to predict accurately when sophisticated technological interventions will be successful not only in keeping the patient alive but in restoring the person to some degree of meaningful functional capacity. There is a strong presumption toward applying fully any available technology that holds any potential for benefiting a patient.

The combination of an aging population and advances in medical technology has had an enormous impact on increasing total health care costs in the past 20 years. Providing more units of more sophisticated (as well as routine) care has resulted in an ever-larger public and private economic investment in the health care industry. A concerted effort is under way in this Nation to attempt to curb excessive health care spending, through, for example, reimbursing hospitals prospectively for Medicare patients under a diagnosis-related group formula. But increasing quality for increasing numbers of older, sicker patients costs a great deal. The delicate cost containment/quality balance carries the potential for further challenging the medicine/law relationship.

All the changes arising out of demographic and technological trends have affected the modern relationship between medicine and law. They have raised new substantive medicolegal questions, and fostered new legal approaches or processes to address them. There was no need to determine the appropriateness of withholding or withdrawing life-sustaining technologies such as ventilators, feeding tubes, and antibiotics when these technologies did not exist. There was no need to determine the legal status of a person with irreversible cessation of brain activities but artifically maintained breathing and heartbeat at a time when most patients either clearly died or clearly recovered. There was no need to agonize over forcing hemodialysis on a demented, unwilling patient before that technology became available (and before the aging of the population contributed to so many patients falling into that category).

We have new legal issues because we have options today that previously did not exist; our modern medicolegal dilemmas are largely the product of our successes. It is not that the law today intrudes into matters that were previously resolved privately; the law gets involved today in many matters that formerly did not come up at all and therefore did not need to be resolved, privately or publicly.

Thus, medicine and law are more closely intertwined than ever before, particularly regarding issues of life-sustaining technologies and the elderly. How this intertwining is perceived will largely determine whether it acts as a positive or negative force in making and acting on decisions.

HEALTH PROFESSIONALS' PERCEPTIONS OF THE LAW

Differing Perceptions of the Law

Physicians and Nurses

Physicians fear liability for civil suits or criminal charges. Rising malpractice settlements and insurance premiums in the 1980s have increased physicians' concern about malpractice suits. Articles entitled "Diary of an Unfounded Malpractice Suit" (Riccardi, 1985), "Who Can Sue You for Not Rendering Care" (Horsley, 1984), and "How a Lawyer Decides Whether to Sue You for Malpractice" (Rheingold, 1985) convey this sense of fear and threat. Physicians worry that plaintiffs' attorneys can bring suits, even if there have been no medical or ethical mistakes.

Criminal liability for withholding life-sustaining treatment also concerns caregivers. In 1982, two California physicians were charged with first degree murder after discontinuing mechanical ventilation and intravenous fluids on a patient who remained comatose after a cardiac arrest (Barber and Nejdl v. Superior Court of the State of California, 1983; Lo, 1984). The family had asked that this treatment be withdrawn. These unprecendented criminal charges were dismissed by a court of appeals. But many physicians feared that they could face similar criminal charges, even if they follow ethical and medical guidelines.

Concerns about criminal liability may persist even though such prosecutions are extremely rare and would be unlikely to succeed (Green, 1984; Oakes, 1982). Even a slight risk of criminal charges, with adverse publicity and stigma, may influence physician behavior. Physicians' worries increase when district attorneys make such statements as: "Take away food and water and I'll prosecute to the fullest" (Ginex, 1982). Later, after attending a medicolegal conference, this prosecutor said that he had changed his mind. But such incidents may only reinforce physicians' fears that the law is inconsistent and that lawyers are uninformed about life-sustaining treatment. Resulting perceptions may compel the provision of medically futile, purposeless treatment to a dying patient, or might lead to maintaining someone on artificial life-support systems even after brain death has been clinically observed, until a court order for treatment cessation has been obtained.

Some physicians believe the law impedes good medical care for patients. Doctors who feel that they make complicated life-and-death decisions under great time pressures may resent having their decisions later second-guessed by judges and lawyers. Some physicians understandably doubt that judges and lawyers can make good decisions about patient care, because the legal system seems too slow for the exigencies of these situations. When decisions are appealed, maximal care is usually continued, and patients often die during the appeals process. The most forceful expression of such physician hostility toward the law was an editorial in the prestigious New England Journal of Medicine concerning the Saikewicz case: "To judges, in Massachusetts or elsewhere, who believe that the judiciary should routinely take responsibility for life-or-death decisions in the incompetent terminally ill patient, I respectfully suggest a guided visit to a large acute-care hospital, particularly to the pediatric and adult intensive-care units, where they can take sober cognizance of the numbers of urgent and complex medical problems that would have to be adjudicated in their courts" (Relman, 1978). An experienced and respected health care lawyer has also warned of the intrusion of law into medical practice: "Few trial court judges regard their role as necessarily positive, either for the patient or the legal process.... Our legal system, with all of its very positive virtues, cannot replace the more intimate struggle among those caring for the patient and those who care about the patient, to resolve many of these questions" (Rothenberg, 1982).

Physicians are often antagonistic toward judges and lawyers as well. They blame judges for rulings that undercut physicians' ability to practice medicine. Similarly, they blame plaintiffs' lawyers for bringing unfounded civil suits. Such hostility by physicians toward another profession may be an attempt to assign blame for their own decreased autonomy and authority. Although the rhetoric is phrased in terms of benefiting the patient, an underlying issue may be loss of control and power by physicians, or even economic gain by the continuation of services.

The apparent inconsistency in the common law often confuses physicians. As discussed later in this paper, case decisions in different States about life-sustaining treatment may be susceptible to different interpretations on such issues as whether physicians and families of incompetent patients can decide to withhold such treatment without going to court. Furthermore, the common law is unavoidably uncertain in the mediolegal sphere, as in other areas. If the clinical circumstances of a case differ from the situations in previously decided cases, physicians cannot be sure that the previous rulings apply. In addition, in some states there are no test cases and therefore no precedents about life-sustaining treatment. Such uncertainty may frustrate physicians who seek guarantees that they will not face liability for withholding treatment.

Physicians are bothered not only by case law, but also by administrative regulations and statutory law that carry out political decisions. They believe such legislation imposes some unrealistic demands and embodies unwise social policies. For example, Medicare regulations for Federally funded hospice programs require physicians to certify that patients are terminally ill and will not survive more than 6 months (Brody and Lynn, 1984; Fraser, 1985). If patients survive longer than this, the hospice bears financial responsibility for their care. Such accurate prognostication, however, is beyond the scope of medical knowledge. In order to avoid admitting patients to hospice who survive longer than 6 months, physicians would have to admit only those they expect to survive 2 or 3 months. As a result, many patients who will in fact live only 6 months are denied hospice care until the final stages of their illness. Furthermore, Federal regulations impose costly programmatic requirements on hospices that receive Medicare payments, replace volunteerism with bureaucracy, and introduce financial incentives that conflict with hospice philosophy. For these reasons, most hospices have elected not to seek certification for Medicare reimbursement (Fraser, 1985). Many physicians believe these Federal regulations carry out unsound policy decisions that compromise the goal of hospice to provide supportive care.

Given these legal fears and uncertainty, physicians may seek prior assurance in the courts that their proposed actions will not expose them to liability. Ironically, when physicians or hospitals seek declaratory relief from courts, they exacerbate the very situations they decry: slow judicial decisions that intrude on medical practice.

Nurses have different perceptions of the law than physicians do. They may face legal liability if they carry out physicians' orders that violate ethical or legal principles. They have become increasingly concerned about their own legal responsibility and liability. Nurses implement do not resuscitate (DNR) orders. They are usually the first people to respond to a cardiac arrest and initiate resuscitation. If an order not to resuscitate the patient is made against the wishes of the patient or the family (and contrary to ethical and legal principles), the nurse may bear legal responsibility for withholding resuscitation. Conversely, if a nurse knows that the patient does not want resuscitation but the physician declines to write a DNR order, the nurse could be in legal jeopardy for carrying out resuscitation. An even more difficult situation occurs when the physician gives an oral order not to resuscitate the patient, but deliberately does not write a formal order in the chart. Nurses who follow such oral orders have no documentation that physicians told them not to resuscitate, and hence they risk legal liability. For these reasons, nurses may request that a hospital set up explicit DNR policies.

For nurses, ethical dilemmas usually involve disagreements with physicians (Howell, et al., in press). Nurses increasingly seek a more active role in patient care (Prescott and Bowen, 1985). They believe that since they spend more time with patients and families, they may know better than physicians what patients want or what is best for patients. One philosopher has suggested that an important change has occurred in the role of nurses (Winslow, 1984). Previously the metaphor of loyalty to a commander was used. But now, rather than playing a subordinate role to doctors, nurses are seeking the role of patient advocate.

This new role, however, may clash with the hierarchical power structure of hospitals. It may be difficult for nurses to question orders by physicians. Ironically, nurses may find that their concerns over their own legal liability provide an effective way to play a more active role. They have been able to change hospital policy, for example, in setting up formal policies for DNR orders. In turn, the existence of these policies may allow nurses to raise ethical concerns in particular cases and thus play a more active role in decisions.

A dramatic example of this is the Barber and Nejdl case (Barber and Nejdi v. Superior Court of the State of California, 1983). As mentioned earlier, two physicians were charged with first degree murder after discontinuing life-sustaining treatment on a patient who was comatose after a cardiac arrest. The case was brought to the attention of the district attorney by a nurse from the intensive care unit. She had insisted that the attending physicians, not the nurse, disconnect the ventilator. Later, when the patient continued to breathe by himself, she asked the physicians to order a misting device. The nurse and one of the physicians had a vehement public confrontation over whether a misting device was necessary. The physician believed that the nurse was insubordinate, while the nurse believed that the physician was belittling her suggestions to improve patient care. Her recourse to the legal system was a dramatic response to this disagreement. Although all legal issues were ultimately settled in favor of the physician-defendants, this case illustrates how poor working relationships with nurses may increase legal problems for physicians.

Other Professionals Whose Views Affect Perceptions

Others in the health care system may have different perceptions of the law. Hospital administrators wish to minimize legal problems, the cost of defending lawsuits, and bad publicity. Their primary responsibility is to the hospital corporation, not to its physicians, nurses, or patients. They may be unwilling to accept even minimal legal uncertainty over withholding life-sustaining treatment, and may recommend continuing such treatment or may insist on going to court for prior legal clarification, as happened in the Bartling case (Bartling v. Superior Court of California, 1984).

Often administrators are more concerned about the legal risk of withholding life-sustaining treatment than of continuing possibly inappropriate treatment. Although the patients or their families have brought several suits against physicians and hospitals to have treatments discontinued or alleging battery for unconsented-to treatment, hospital administrators seem more willing to accept these legal risks. In general, neither adverse publicity nor large monetary settlements have been the outcome. In one recent case, an Ohio Common Pleas Court (trial level) allowed mechanical ventilation to be discontinued on a woman with amyotrophic lateral sclerosis who was in a persistent vegetative state after a cardiac arrest (Leach v. Akron General Medical Center, 1980). The patient's husband subsequently also brought a civil suit alleging battery for treatment inflicted over family objections, which was dismissed (Estate of Leach v. Shapiro, 1984). Hospitals and physicians can justify to themselves their actions in continuing life-sustaining treatment; in trying to benefit their patients, they believe it is appropriate to err on the side of continuing life in difficult cases. The public (and judges) seem willing thus far to accept this justification.

Administrators are concerned about the legal liability of the institution, as contrasted with physicians' concerns about their individual liability. Lack of formal institutional policies, for example about DNR orders, may create liability for the institution. Thus, administrators may be more concerned than physicians are about instituting hospital policies. Indeed, some physicians may be cynical about such guidelines, considering them impractical or even counterproductive. In such disagreements, the law may become a scapegoat.

Administrators also must deal with regulations and financial pressures that affect physicians only indirectly. For example, when a patient is decertified by Medicaid as not needing acute care hospitalization, the hospital will not be reimbursed for that patient's care. Physicians may feel trapped because their responsibility not to harm the patient conflicts with their responsibility to maintain the fiscal integrity of the hospital.

Similarly, under prospective payment by Medicare diagnosis-related groups, the hospital has financial incentives to discharge or transfer terminally or chronically ill patients out of the hospital as early as possible. However, the physician who actually orders the transfer does not face the same direct financial pressures. Under current prospective reimbursement systems, the hospital bears the direct financial risk, not the physician. While the hospital is given a fixed sum regardless of the length of hospitalization, physicians can charge professional fees for each day of hospitalization. Caregivers may believe such transfers harm terminally ill patients by disrupting continuity of care and causing psychological harm (Lind, 1984). This difference in perspectives may lead to clashes between physicians and hospital administrators, with both parties blaming the legal or political systems.

Lawyers may perceive their role in different ways, depending on the identity of their client. Some lawyers may wish to help physicians and administrators minimize liability. They may point out all legal risks and recommend the course of actions that poses the least legal risk. For these lawyers, patient and family welfare is of secondary, if any, importance. Others may view their role as helping to weigh the legal liability or uncertainty against other considerations, such as ethical and medical principles for decisionmaking. Still others may see their task as preparing to defend the decisions made by physicians in good faith and in accordance with institutional and professional guidelines.

Hospital lawyers are more likely than physicians' lawyers to be consulted when the withholding of life-sustaining treatment is being considered. Few physicians retain lawyers whom they can consult about possible legal risks before they make such decisions. But it may be unwise for physicians to rely on hospital attorneys for legal advice. Hospitals may have different legal liabilities and concerns. There may even be a conflict over whether the hospital or the physician is liable. Indeed, when faced with a malpractice suit, physicians frequently are advised to obtain legal counsel that is separate from the hospital counsel (Kaplan, 1984). This potential conflict of interest may be especially common when physicians have their malpractice premiums paid by the institution, as in health maintenance organizations or university teaching hospitals.

Risk managers (many of whom have not been to law school or had other training in legal matters) are hired by hospitals to minimize financial and legal liability for the hospital. Their work includes implementing quality assurance programs, identifying potential problem areas, investigating accidents or incidents, and determining when to negotiate out-of-court settlements. When a lawsuit is brought, the risk manager prepares or coordinates litigation. Fearing large settlements by sympathetic juries, risk managers may wish to settle some suits out of court for low payments even if claims may not be meritorious. This approach may seem more cost-effective than spending money for legal fees and risking a larger settlement in court (Danzon, 1985).

Risk managers also give a great deal of prospective advice to medical and nursing staff on how to avoid legal difficulties. For many physicians and nurses, risk managers are the chief source of "legal" guidance. Such guidance is usually biased toward continuation of life-sustaining treatment for the dying patient.

Insurance companies wish to minimize their expenditures for defending against and compensating patients who bring suit. Hence, they too may seek to settle some cases out of court even when the plaintiff does not have a strong case, rather than bear the expense of litigation and risk larger verdicts by a jury. Although this strategy is pragmatic and reasonable from the viewpoint of the insurance company, some physicians named in questionable suits may wish to pursue a different strategy. Physicians do not pay the costs of the settlement or verdict directly and some may be concerned about vindicating their reputations. If they are outraged by what they consider unfounded suits, they may seek exoneration in court. Physicians may perceive out-of-court settlements of unfounded suits as yet another example of how the "legal" system puts them in jeopardy even when they may not be at fault.

Influence of Delivery Setting

Perceptions of the law differ in various sites of practice. In teaching hospitals, responsibility for decisions may be diffused among many caregivers. Attending physicians on the faculty may not be as involved in decisions as are residents, interns, and medical students. In one study, attending physicians, who have legal responsibility for patient care, were involved in decisions to withhold cardiopulmonary resuscitation (CPR) in only 39 percent of cases (Uhlmann, et al., 1984). In the other cases, residents and interns made these important decisions.

Yet, inexperienced physicians and students in teaching hospitals may not appreciate legal and ethical guidelines about life-sustaining treatment. The New York state grand jury in 1983 investigated a case in which a decision to withhold cardiopulmonary resuscitation from an elderly woman was made inappropriately by a medical student without regard to her preferences and without discussing the decision with more senior physicians (Supreme Court of the State of New York, 1983). The grand jury found that the lack of a formal hospital DNR policy contributed to this violation of ethical and legal standards.

Physicians in training may feel insulated from legal concerns for several reasons. They may not understand the relevant ethical and legal issues about life-sustaining treatment. Their malpractice premiums are usually paid by the hospital. The likelihood of their involvement in a future lawsuit seems remote, and attending physicians have ultimate legal responsibility for decisions.

One component of the delivery setting that can influence physicians' perceptions of the law is the reimbursement system. Fee-for-service and prepaid health care systems have different financial incentives, including incentives regarding life-sustaining treatments (McPhee, et al., 1984). In turn, these economic incentives may influence physicians' willingness to assume legal risks. In fee-for-service medicine, life-sustaining treatment generates income for both the hospital and the physician. Hence, physicians may be more likely to continue life-sustaining treatment than to go to court or accept even a small risk of legal liability for discontinuation. In contrast, in prepaid care under prospective or capitation payments, the physician and the hospital may suffer financially if expensive forms of life-sustaining treatment are continued for a long time. This economic incentive may encourage the physicians to withhold life-sustaining treatment even when there is some legal risk. Prepaid systems, however, are sensitive to charges that they would discontinue treatment to save money for the providers. Such charges were alleged, for example, in the Barber and Nejdl case. In reaction, prepaid systems may be very conservative about discontinuing treatment.

Physicians who are salaried and whose malpractice premiums are paid by employers, as in health maintenance organizations or in academic medical centers, may be willing to accept some legal uncertainty in decisions about life-sustaining treatment. In contrast, those in fee-for-service practice, who pay malpractice premiums from their gross income, may be more concerned about increases in premiums for bad ratings. They may also be more concerned about how adverse publicity may affect their practice. In turn, they may be unwilling to accept even minimal legal uncertainty.

Many decisons about life-sustaining treatment for elderly incompetent patients are made in nursing homes rather than acute care hospitals, and there may be a great discrepancy between actual practice in nursing homes and ethical and legal ideals. More than in acute care hospitals, decisions in nursing homes may be made informally without standard procedures or even open discussion among those involved. Anecdotal evidence (Hilfiker, 1983) suggests that decisions about transfer to acute care hospitals or about treatment of infections with antibiotics are often made unilaterally by physicians. Few nursing homes have policies about cardiopulmonary resuscitation or about withholding care (Miles and Crimmins, 1985). Even if such policies exist, they are often vague and poorly disseminated, and compliance may be poor. Physicians spend little time in these facilities. They may visit patients only the once a month that is required by Medicare or Medicaid, unless they are employed directly by the nursing home as medical director. Because they are not actively involved in the nursing home, physicians may regard guidelines about DNR orders and withholding treatment as bureaucratic impositions that do not improve patient care.

Nurses, too, may play a different role in these settings. Because physicians are not as available, nurses may have more responsibility and discretion. To decrease their own legal liability, they may want more explicit procedures for making decisions about life-sustaining treatment and formal, written orders rather than oral ones. Once again, the threat of legal difficulties may lead people to place blame on the legal system, rather than recognizing the underlying ethical problems or institutional shortcomings.

Nursing home administrators have particular concerns with elder abuse laws and licensing requirements. Decisions about life-sustaining treatment undoubtedly will be increasingly scrutinized because of concern about the quality of care in nursing homes and the vulnerability of frail elderly nursing home patients. The New Jersey Supreme Court, in the Conroy decison, noted that nursing home patients may have no family, do not have a close relationship with their physicians, and may be victims of abuse (In the Matter of Claire C. Conroy, 1985). The Conroy ruling declared that every time the withholding of treatment from incompetent nursing home patients is considered in New Jersey the situation has to be investigated by the State Ombudsman as a possible case of elder abuse. The court intended these procedures to protect frail nursing home residents. Nursing home administrators may wish to avoid such investigations, which may be long and expensive and generate adverse publicity.

In response to these dilemmas, nursing home administrators may adopt a legally conservative policy. If there is any perceived risk of legal liability for withholding life-sustaining treatment, they may urge that treatment be given. Alternatively, they may encourage the transfer of patients to acute care hospitals when a medical crisis like pneumonia develops, rather than deciding the question of withholding treatment in the nursing home. Such decisions may not be consistent, however, with the patient's wishes or interests.

Sources of Perceptions

Medical Education and the Legal Community

Medical education gives little attention to ethical and legal issues, especially during the clinical years of medical school and residency. In the preclinical years, there may be courses on medical ethics or, much less commonly, on medical law. But clinical medicine is learned on a case-by-case basis from more senior physicians. Discussions of individual cases on "rounds" and in conferences focus on the biotechnical aspects of medicine, such as what tests would provide the most diagnostic information and what medications would be most effective in a given situation. Legal and ethical issues often are not discussed. Only infrequently are lectures about law and ethics presented during clinical training. Even less frequently are students introduced to the analytical methods and approaches of law and ethics. Most physicians report that they developed their approach to ethical dilemmas through clinical experience, observation of role models, and interactions with medical peers, not through formal coursework, seminars, or conferences (Pellegrino, et al., 1985). Interdisciplinary exposure to legal and ethical analysis is scarce.

Not only is there little attention to the substance or the analytical approach of the law in medical education, but there is also scant attention to physicians' attitudes toward the law and toward legal risk. Medicine is an art involving probability and uncertainty, not an exact science. Medical education is only beginning to deal with probabilities in diagnosis and treatment in a systematic way through techniques like decision analysis. Little attempt is made, however, to teach students and physicians how to approach the uncertainty inherent in ethical dilemmas. As a result, physicians may unrealistically expect more certainty from the law than they do from medical science. At the same time, ironically, they tend to praise medical science as "hard" and condemn law and ethics as "soft."

Few continuing medical education courses devote much attention to legal aspects of medicine. One notable exception is the course recertifying physicians in cardiopulmonary resuscitation, run by the American Heart Association (AHA). Many physicians are required to take this course each year to renew their hospital privileges or medical licenses. The AHA handbook about CPR has a chapter entitled "Medicolegal Aspects of Cardiopulmonary Resuscitation (CPR) and Emergency Cardiac Care (ECC)" (McIntyre, 1983). Its legal advice is conservative and may be at odds with clinical practice. The handbook advises that CPR be administered to almost all cardiac arrest victims who are brought to the emergency room without prehospital CPR, unless an order not to resuscitate has already been appropriately made. Formerly, such patients were designated "dead on arrival." The AHA considers this term an anachronism, because it may be impossible to determine that circulatory arrest has been present for such a long time that recovery of brain function would be impossible: "The argument that the patient could have collapsed. . . and continued to have cardiac activity at a level sufficient to sustain the brain until the victim was rushed through the door of the emergency facility may be an insurmountable one."

The Association suggests it is unwise for physicians to withhold resuscitation based on reports of laypeople who witnessed the arrest and who report long delays in resuscitation: "Armed with the experience that weak or slow pulses may be missed by inexperienced observers, a plaintiff's attorney may inquire as to the person upon whom the physician should reasonably rely as his witness to the onset and progression of the process of brain death" (McIntyre, 1983). Furthermore, an apparently dead patient who has ingested drugs or is hypothermic can sometimes be successfully resuscitated.

The AHA also addresses the question of when resuscitation efforts should be terminated. Often caregivers are concerned that even if the heart is successfully resuscitated, severe irreversible brain damage has already occurred. But there are no reliable criteria that allow caregivers to predict during resuscitation the patient's neurological outcome. The AHA recommends that only failure to restore circulation after basic and advanced cardiac life support is an appropriate reason for stopping resuscitative efforts because of medical futility. The handbook notes that "the concern for guidelines for the cessation of CPR has been strengthened by the reality that litigation is more likely to follow when the patient survives with permanent brain damage than when the patient dies" (McIntyre, 1983).

One major source of information about the law is hospital lawyers and risk managers. Yet, their advice may be incorrect and misleading, as for example after the Saikewicz ruling by the Massachusetts Supreme Court in 1977 (Superintendent of Belchertown State School v. Saikewicz, 1977). Joseph Saikewicz, who had been severely retarded since birth, developed acute myeloblastic leukemia. Using a "substituted judgment" standard, the court ruled that he need not undergo chemotherapy for leukemia. The most controversial part of the decision concerned the proper procedure to be followed in decisions about life-sustaining treatment for mentally incompetent patients. Some lawyers recommended to clients that the decision required that all such decisions be taken prospectively to probate court. Other legal scholars believed that the decision required physicians to go to court only if the case involved a "substitute judgment" or if they desired advance assurances of legal immunity. One expert in health care law objected that "many lawyers advising Massachusetts hospitals on the law of the Saikewicz case lack experience and training in health law and have little familiarity with either medical practice or hospital procedures" (Annas, 1982).

After the Saikewicz decision, physicians in Massachusetts were confused about orders not to resuscitate patients in case of cardiopulmonary arrest. Some legal commentators believed that the Saikewicz decision did not preclude the physician and family from making such orders. However, other lawyers advised that no treatment could be withheld from incompetent patients without a prior court order. The Dinnerstein decision by the Massachusetts Appeals Court in 1978 resolved this legal uncertainty over DNR orders, ruling that the physician and family could appropriately agree on such an order without advance recourse to the probate court (In re Dinnerstein, 1978).

Many attorneys and others (such as ethicists and nonattorney risk managers) who purport to give, or who are interpreted as giving, legal advice to medical professionals about life-sustaining technologies send out mixed and inconsistent signals. This is a complex and rapidly changing subject area, where up-to-the-minute information (about, for instance, trial level action or a proposed bill in another jurisdiction) is frequently difficult to monitor and rumors and misinformation abound. Unless attorneys and other advisors have a proper background in the first place (and some people question whether nonattorneys have a sufficient background) and put substantial time and effort into continuing educational pursuits about legal issues surrounding life-sustaining technologies, it is easy for confusion and misunderstanding to develop among advisors. This confusion is often transmitted to medical professionals in the form of ambiguous (both actual and perceived) legal advice, which tends to diminish confidence in the law.

In addition, ambiguity in legal advice may also translate into legal ultraconservatism and risk management at any price. It is certainly understandable that medical professionals and institutional administrators and trustees who stand on the firing line daily encountering the perplexing dilemmas of decisionmaking about life-sustaining technologies are deeply interested in preserving their own legal integrity--that is, in avoiding lawsuits (or, at least, successful lawsuits). One can also appreciate the legal prophylaxis orientation--and consequently the highly conservative bias--of professionals who must advise medical professionals on how to minimize their potential exposure to legal risks. The appeal of security and risk avoidance, the quest for a zone of legal "comfort" (Annas, 1984a), is self-evident. Since medical professionals value advance legal certainty and protection so highly, it is not surprising that those who provide risk management counsel regularly issue advice that exhibits a heavy, arguably excessive, prejudice toward narrow and conservative solutions (that is, tending to rely on the advance assurances available only through the formal, legal, adversarial process) (Kapp, 1985a; Kapp, in press).

The Professional and Popular Media

Articles in medical journals about the Saikewicz and Dinnerstein decisions purported to inform many physicians about these rulings. Such articles, however, may be incorrect. One legal scholar attacked legal advice columns as "casual, offhand, misleading, or just plain wrong" (Annas, 1982).

Statutory law as well as case law can be presented incorrectly in medical journals. One article on advance directives, for example, did not realize that under the California statute on the durable power of attorney for health care, surrogate decisionmakers must follow the previously expressed wishes of patients (Schneiderman and Arras, 1985). The article therefore incorrectly criticized the durable power of attorney for health care for not respecting patients' preferences regarding treatment.

Articles about the law are often found in "throw-away" journals that are commonly funded by drug companies and do not have a peer-review system (Kaplan, 1984; Rheingold, 1985; Riccardi, 1985). The articles may highlight concerns about a malpractice crisis and polarize attitudes toward attorneys; they often suggest that even if physicians practice good medicine, they may be trapped into lawsuits by unscrupulous attorneys or greedy patients. Hence, these articles may heighten physicians' fears and sense of powerlessness.

The lay press, which often gives extensive immediate but not continuing coverage to "landmark" cases, shapes professional and public perceptions about the law. Publicity often heightens physicians' perceptions about the hardships of legal proceedings. For example, Drs. Barber and Nejdl, who were indicted for murder for discontinuing life-sustaining treatment, received great publicity, some at the urging of their defense attorneys who believed informing the public about the issues would increase their chances for acquittal (Lo, 1984). This publicity, however, brought with it severe personal and professional burdens. Other physicians, fearing such disruption of their private lives and careers, may be reluctant to make medical decisions that entail even a slight risk of legal charges.

Publicity may also polarize disagreements about life-sustaining treatment, as in the case of Elizabeth Bouvia (Elizabeth Bouvia v. County of Riverside, 1984; Steinbrook and Lo, 1986). Bouvia is a woman, almost quadriplegic from cerebral palsy, who entered a California hospital in 1983 at the age of 26, saying that she wanted to starve to death. Her physicians and the county hospital believed that her request would involve caregivers in a suicide and that it violated the rights of other patients who were in the hospital and who had chronic diseases. A court rejected her petition to prevent feeding against her will and later authorized involuntary tube feedings. Under the glare of publicity, hostility and confrontation developed. Disabled individuals held vigils at the hospital to convince her to change her mind. Nurses took notes on her visitors and her telephone calls, which were later used as evidence against Bouvia in court. A national columnist's offer to raise funds for her medical treatment was rebuffed.

An escalating cycle of opposition and polarization developed. Physicians and hospital administrators reading the news stories might well conclude that such cases are time-consuming, stressful, and best avoided. The course of events seemed beyond the control of physicians and administrators; turning to the courts for a solution seemed the only recourse. But press coveage did not suggest how physicians and administrators might have managed the case without going to court.

With difficult, hostile, or demanding patients, effective care requires a partnership between the doctor and patient. In the Bouvia case, such a partnership appeared difficult or impossible. But it was essential to try to build it, because the alternative of having the courts decide was unsatisfactory. In general, physicians can take steps to try to establish a therapeutic relationship. Spending time listening uncritically to the patient may be useful. If the patient's requests contradict good medical practice or ethical guidelines, physicians need to define their limits sympathetically. In discussing shared and realistic goals, physicians might stress their empathy for the patient's symptoms and frustration. In the Bouvia case, these principles may have been overlooked. Her physical limitations made it difficult for her to have a sense of partnership in her care. But such patients might be given control over the hospital routine, such as the timing of blood tests and toilet care. Enhancing a patient's sense of control may lead to agreement over a plan of care. Physicians reading about the Bouvia case in the newspapers might have overlooked the therapeutic value of the doctor-patient relationship. In turn, they might have inferred that only the courts can resolve such difficult cases.

Media coverage of the Bartling case also suggested that physicians cannot resolve ethical dilemmas, and that only the courts can decide (Bartling v. Superior Court of California, 1984a; Lo, 1986). William Bartling was a 70-year-old man with chronic obstructive lung disease who was admitted to the hospital for depression and chronic back pain. When a chest x ray showed a new pulmonary nodule, a needle aspiration was performed, which showed carcinoma of the lung. After the procedure, he required mechanical ventilation. Over the next 2 months, he could not be weaned from the ventilator. He and his family asked that the ventilator be discontinued. The hospital and his physicians refused, and he went to court.

A deposition by the patient was videotaped and televised by "60 Minutes." Bartling nodded yes when asked if he wanted to live, but not on a ventilator, and when asked if he understood that if the ventilator was discontinued, he would die. This brief interview seemed to establish the patient's wishes. However, caregivers claimed that Bartling changed his mind about the ventilator, depending on whether or not he was depressed. The questioning in the deposition did not check whether he had changed his mind or was ambivalent, whereas such questions would be customary in a clinical interview. Since these issues were not raised, the possibility that the disagreement might be resolved if his depression could be effectively treated was also not considered.

Physicians may have felt uncomfortable that the legal system did not consider the medical issues in as much detail as a medical conference would. They might object that the ruling seemed based on an inadequate discussion of the medical situation. Caregivers then might fault the legal sustem as medically naive and inaccurate.

The presentation of the case in the media implied that court action was the only way to resolve the disagreement. It did not present a less dramatic alternative--that agreement might be possible through improved communication between caregivers and the patient or by psychological treatments. On the one hand, Bartling might agree to treatment for his depression. On the other hand, if physicians were convinced that his refusal of treatment was truly informed and consistent, they might be willing to accept his wishes. In summary, accounts of dramatic cases in the media do not indicate how physicians, using their skills of interviewing and counseling, might resolve disagreements with patients. Thus the media implicitly suggest that the only way to resolve ethical dilemmas in clinical medicine is to let the courts decide. At the same time, physicians may infer that legal rulings are not based on an adequate assessment of the medical issues.

Uncertainty in the Law

Current law is less than certain and definite concerning life-sustaining technologies or almost any other topic. This lack of certainty affects the way that medical professionals perceive the law and its impact in this area.

First, there is general agreement across legal jurisdictions (i.e., among the different States) on the substantive issues. In the absence of countervailing compelling State interests, a competent adult has the right to accept or refuse any medical treatment, including life-sustaining technologies; the wishes of a previously competent patient, to the extent that they can be reasonably discerned, should govern the medical treatment of that individual (known as substituted judgment); and where there is no factual basis for engaging in substituted judgment (i.e., it is impossible to know what the patient would have chosen if able to make a choice), the best interests of the patient, as judged according to the proportionality or benefit/burden test, should control treatment decisions. (For a fuller discussion of these principles, see the paper by Buchanan, et al. in this volume.) The countervailing State interests that have been identified as potentially compelling, depending on the facts of the particular case, are prevention of suicide, preservation of life, protection of innocent third parties, and maintenance of the ethical integrity of the health professions (see, e.g., Bartling v. Superior Court of California, 1984a).

There is a good deal of variation, however, among legal jurisdictions regarding procedural issues--who should make decisions when the patient cannot communicate and under what process surrogate decisionmaking should be made. This variation contributes to anxiety and apprehension in the way the medical professional perceives legal requirements.

A number of legal jurisdictions have not dealt with life-sustaining technology issues at all, leaving a perceived vacuum. Thirty-six States had enacted natural death or living will statues by the end of 1985 (Society for the Right to Die, 1985); although there are similarities among most of these statutes, there are notable differences as well. Differences also exist among jurisdictions concerning use of the durable power of attorney for health care decisionmaking. A few States have enacted statutes specifically making the durable power of attorney applicable to health care, a few have included the naming of proxies in their living will statutes and thus arguably make it applicable only to terminally ill patients, and many States have not made any attempt to define the scope or limits of the durable power of attorney vis-à-vis health care.

Among the State court cases that have grappled with life-sustaining technology issues, numerous procedural approaches have developed on either a voluntary or mandatory basis: prognosis committees (In re Quinlan, 1976; In re Colyer, 1983), institutional ethics committees (In re Torres, 1984), nursing home ombudsmen (In re Conroy, 1985), the involvement of county coroners and prosecutors (Leach v. Akron General Medical Center, 1980), reliance on family and physician (Barber and Nejdl v. Superior Court, 1983; Matter of Dinnerstein, 1978; Matter of Spring, 1980), use solely of the patient's prior statements (In re Eichner, 1981; In re Storar, 1981), reliance just on the court as decisionmaker (Superintendent of Belchertown State School v. Saikewicz, 1977), and so on.

Understandably, medical professionals may feel confused and intimidated by this plurality of legal approaches. Several particular issues stand out. Jurisdictions apparently disagree on whether the withholding or withdrawing of artificial methods of feeding and hydration from incompetent patients is ever appropriate. In at least two states, courts have ruled (Barber and Nejdl v. Superior Court, 1983; In re Conroy, 1985) that artificial feeding and hydration are to be considered exactly like any other life-sustaining medical intervention, susceptible to being withheld or withdrawn under the substituted judgment and proportionality standards. Yet, 17 of the States with living will statutes have provisions in those acts that make the status of artificial nutrition and hydration problematic (Society for the Right to Die, 1985). Most of the statutes (those of Colorado, Connecticut, Florida, Georgia, Illinois, Indiana, Iowa, Maine, Maryland, Missouri, New Hampshire, Oklahoma, Tennessee, Utah, Wisconsin, and Wyoming) specify that artificial nutrition and hydration are not included in the definition of life-sustaining treatments that may be withheld or withdrawn.

A recent Florida court decision (Corbett v. D'Allesandro, 1985; Whiteneck, 1985) refused to permit withdrawal of artificial feeding and hydration from a patient because the state living will statute expressly excluded these procedures. At least one living will statute (Arizona's) appears to say that artificial nutrition and hydration needed for patient comfort may not be withheld or withdrawn, implying that, when it is not necessary for patient comfort (i.e., when the patient cannot experience hunger or thirst), it may be withdrawn. There has been no judicial clarification of this point as yet. A further complicating factor is the Federal "Baby Doe" regulations (50 FR 14878; 45 CFR 1340), which forbid the "inappropriate" withholding or withdrawing of artificial feeding or hydration from a handicapped newborn, without further definition.

The legal authority of the family to make decisions on behalf of an incompetent patient is another issue that illustrates an inconsistency across legal jurisdictions that contributes to medical professionals' unease and defensiveness. As a general matter, in the absence of a court order finding a person mentally incompetent and appointing another to act as guardian, neither the family as a whole nor any of its individual members have any special legal authority to make decisions on behalf of a family member who cannot communicate decisions (Ad Hoc Committee on Medical Ethics, 1984). Nonetheless, it has long been the medical convention to rely on families as decisionmakers for incompetent patients, even in the absence of express legal power.

A number of States now formally recognize the family role. Courts in at least five States have explicitly recognized the authority of the family to exercise the incompetent patient's rights on that person's behalf. Eight of the existing living will statutes expressly provide for termination of treatment of incompetent patients who have not executed an advance directive (living will or durable power of attorney) (Society for The Right to Die, 1985). The decision under these statutes typically is made with the agreement of the attending physician and, in a stated order of preference, the family members.

It should be borne in mind that inconsistencies among States are mitigated greatly by the fact that most physicians practice medicine in only a single legal jurisdiction. Thus, as long as the physician understands the law in his or her own State, the fact that other States may have different rules is of little practical consequence in the physician's daily activities.

Even in the absence of explicit judicial or legislative authorization in a particular State, a medical professional's legal risk for a good faith decision made in conjunction with an incompetent patient's family is virtually nil. Nevertheless, such decisions are, in legal jurisdictions that have not yet ruled on this subject, made and implemented under a cloud of some uncertainty that raises the anxiety level of medical professionals.

Myths About the Law

There are several possible explanations for the growth of erroneous and negative perceptions concerning the law's impact on decisions about life-sustaining technologies. (Kapp, 1986). First, as noted earlier, many medical professionals labor under an honest but unfortunate misunderstanding of what the law is and what it requires. Legal pronouncements often are attributed to courts and legislatures that have no basis in fact.

Second, as indicated, many attorneys and risk managers who advise medical professionals and institutions in life-sustaining situations err greatly on the side of legal conservatism, to the point where their caution in seeking absolute legal immunity before any action is taken wastes time. energy, and emotion in a way that is a disservice to both the client and affected patients and families (Annas, 1984b; Kapp, 1985a; Kapp, 1986).

A conservative, formality-based bias toward risk management in situations of decisionmaking concerning life-sustaining technologies is simple to comprehend, but it is also deeply unfortunate. In a number of ways, such an approach neglects or disvalues other, seriously significant factors that should figure prominently in the calculus of withholding or withdrawing life-sustaining treatment. Hence, this sort of approach is likely to yield neither an optimal decisionmaking process nor the "best" substantive decisions (Annas, 1981; Burt, 1981; Rothenberg, 1982). Perhaps the worse effect of such an approach is that medical professionals may become imbued with the false belief that the formal, legalistic manner of dealing with difficult medical decisions is the best, or even the only, course of action.

Third, and perhaps most importantly, the tendency to blame the law for intractable decisionmaking problems partially represents a conscious (though more often an unconscious) attempt to circumvent the difficult and fundamental ethical, social, psychological, and economic issues that are implicated in decisions about life-sustaining technologies, instead of directly confronting those issues (Cassel, 1985; Kerschner, 1985). The law may be a more attractive opponent to face than the patient's incurable condition, as well as a source of social validation ("hand holding") for decisions for which the physician does not wish to bear responsibility alone (Cassel, 1985). Physicians are professionally conditioned to feel a sense of personal failure when a patient dies. The law is often cited, and lawsuits threatened, to promote the personal emotional needs and agendas of the participants, as a way to flex muscles and let out frustrations (Hofmann and Smott, 1985). It is instructive that in Canada, where a different legal system makes the fear of malpractice actions much less of a factor, issues and practices in decisionmaking about life-sustaining technologies seem just as troubled and unclear as in the United States (Clayton, 1985; Law Reform Commission of Canada, 1979). This phenomenon underscores the argument that the central issues and practices are fundamentally ethical rather than legal.

Whatever the cause, it is easy for the law to become a scapegoat and the focal point of several myths that may interfere with good medical decisionmaking and practice. Many of these commonly heard myths are both wrong and internally inconsistent. The best interests of both medical professionals and their patients compel a critical analysis and refutation of some of the more prominent ones.

The Myth of Simplicity

First, decisionmaking concerning life-sustaining technologies is expected to be clear, unambiguous, and straightforward, and legal interference in medical affairs is thought to make that process unnecessarily and counterproductively complex, uncertain, and difficult. The short answer to this attitude is that irreversible life-and-death decisions are and should be agonizing and gut-wrenching, dealing as they do with the most basic of human values and concerns. Such decisions should never become commonplace, facile, or matter-of-fact (Meier and Cassel, 1983). "The awesome and unsettling power to influence when death comes to another human being should be exercised with the greatest care" (Dresser and Boisaubin, 1985).

To a certain extent, a degree of ambiguity in the law is unavoidable and healthy. There are no absolute guarantees in law, any more than there are perfect guarantees in medical care. Here, as elsewhere, law and medicine operate in parallel. Uncertainties exist in all parts of life; we can to a large extent identify, soften, and prepare for those uncertainties, but we can never completely eliminate them. If medical professionals refused to proceed in the face of clinical uncertainty, no patient would ever be treated; every intervention involves medical risk. Similarly, every intervention involves legal risk as well, but the risk is reasonable and manageable. Particularly in a part of the universe as dependent on human value judgments as our legal system is, some risk can never be obliterated, nor should it be. To the extent that the law contributes to a careful and cautious consideration of all relevant issues and perspectives, to the extent that the law poses questions that would not otherwise have been posed, it makes a valuable and positive contribution to sound decisionmaking (Baron, 1984; Burt, 1984).

The Myth of Intrusion

One widely shared belief is that gratuitous, unwanted, inappropriate legal involvement pervades and intrudes into virtually every aspect and instance of decisionmaking concerning life-sustaining technologies. While it is true that every aspect and instance of medical care (and of every other human activity in complex modern society) entails potential legal implications to which participants must be sensitive, legal intrusion in this sphere cannot fairly be characterized as either gratuitous or pervasive.

First, it is understandable that a few well-publicized legal cases, especially when they yield seemingly conflicting conclusions, are capable of generating substantial anxiety and overcautiousness and increasing the medical professional's normal propensity to practice defensively. However, an examination of the numbers belies the paranoia. Such cases are indeed few and far between. (See report by Annas and Glantz in this volume, and Helm, 1985.) Given the predictable regularity with which decisions concerning life-sustaining technologies are made every day in hospitals and nursing homes across the country — when treatment is either instituted, continued, withheld, or withdrawn — the number of situations in which the legal system becomes actively involved is relatively small. The possibility of a physician, nurse, or health care administrator becoming an involuntary litigant based on a decision concerning life-sustaining treatment of a patient pales in comparison to the ordinary malpractice exposure encountered in standard, run-of-the-mill medical practice.

On the criminal side, both case law and scholarly commentary opine that there is little realistic risk of prosecution or liability whether life-sustaining treatment is or is not given, as long as the decision leading to that result has been made in good faith and according to reasonable professional standards and judgment (Matter of Spring, 1980; President's Commission, 1983; Oakes, 1982; Wilson, 1985; see also Annas and Glantz in this volume). Much media attention surrounded the only criminal prosecution brought against physicians for withdrawing life-sustaining treatment from a comatose, terminally ill patient (discussed earlier) (Barber and Nejdl v. Superior Court, 1983), but many seem to forget that this case ended in complete legal vindication for the accused physicians and an admonition that criminal prosecution was inappropriate.

The bulk of litigated cases fall within the civil sphere. Few involve an after-the-fact allegation of professional malpractice and a demand for substantial monetary damages (but see Estate of Leach v. Shapiro, 1984). Instead, most civil cases involving life-sustaining technologies treat the rare situation of unreconciled differences between participants as to the appropriate course of conduct to follow, and take the form of before-the-fact actions for declaratory and injunctive relief brought by physicians or health care administrators to obtain advance legal prophylaxis or by patients or their families to compel providers to take or to refrain from taking certain actions.

In this regard, it is important to remember that the law is not a self-initiating or enforcing process; it does not simply "happen." Judges do not randomly roam the halls of intensive care units in sweeping black robes with law books under their arms looking for new cases to decide. On the contrary, a tradition of judicial deference is well-established, and a court becomes involved only when an issue is brought to it by an interested party. In many respects, resort to the courts represents a regrettable failure of informal means of resolving such deeply personal dilemmas (Rothenberg, 1982), and challenges responsible medical professionals, patients, and families to devise and implement better means of informal communication, cooperation, and issue resolution (Hofmann and Smott, 1985; Mariner, 1984). In the vast majority of situations, such procedures are not only achievable, but are already being carried out daily (American Geriatrics Society, 1985; Bollet, 1985; U.S.Congress, 1984).

It should also be noted that, even for the small percentage of disputes about life-sustaining technology that become legal cases, not all involve the debilitated elderly. Many have involved young or middle-aged adults, or minors whose parents have refused treatment for them (In re Quinlan, 1976; Brophy vs. New England Sinai Hospital, 1985; Classen, 1985). In fact, older persons are vastly underrepresented as malpractice plaintiffs generally, since their cases represent difficult evidence problems regarding damages and causation.

There will be some circumstances where differences involving issues that raise fundamental values, rights, and interests cannot be satisfactorily reconciled by the parties themselves. Impasses may result from a clash between sincere but uncompromising positions held by different parties, or because of hidden agendas promoted by persons who do not have the patient's best interests foremost at heart. In either case (and such impasses are relatively rare), the judicial system may be the most appropriate decisionmaking forum of last resort--not because judges are automatically imbued with greater wisdom than others, but because the courts can provide a degree of objectivity, fairness, and authority that is unmatched by any other societal or individual formal arena of issue resolution (Baron, 1984; Dresser, 1985).

The Myth of Unreasonableness

Another myth holds that the law surrounding decisionmaking about life-sustaining technologies is basically inconsistent with sound clinical judgment, reason, and ethical imperatives; that it is formulated in a vacuum, based solely on abstract theory, and out of touch with clinical realities. The assumption is that "changes in the law" (generally unspecified) are needed to allow more ethically and clinically reasonable care (Sherlock and Dingus, 1985). As one author prefaced her call for such changes, "Since [the law] does not consider patient sensibilities or base decisions on individual need and sound bioethical principles, . . ." (Whiteneck, 1985).

We hear voiced a lack of faith in the ability of the political system (e.g., hospice statute and regulations) and the common law (law as announced by courts in the context of individual lawsuits, with decisions based on general societal principles, customs, traditions, and legal precedent in similar factual cases) to adapt reasonably to emerging issues concerning the use of life-sustaining technologies. It is not unusual today to hear criticisms by medical professionals, in response to their interpretations of legal decisions, that the law, legal system, and lawyers act as an essentially negative force in medical decisionmaking, a force that often flies in the face of good clinical judgment, sound ethical principles, and human compassion (Connery, 1980). We hear complaints often about the unnecessary cost and turmoil of "defensive medicine" and the need to "treat the attorney" rather than the patient or the family. One influential group of physicians who are quite familiar with life-sustaining technology issues has written that "fear of legal liability often interferes with the physician's ability to make the best choice for the patient" (Wanzer, 1984).

Certainly, in the area of life-sustaining technologies, the state of the law is not definitively settled, and anomalous legal decisions may occur in any sphere of developing, evolving social policy. For the most part, though, the developing law concerning life-sustaining technologies appears to be highly consistent with, and supportive of, clinical judgment, reason, shared ethical precepts, and compassion for the emotional and spiritual well-being of all participants in this human drama (Ball, 1984; Baron, 1984; Lo, 1984; Dresser, 1985; Dresser and Boisaubin, 1985).

To begin, judges recognize that good law, as well as good ethics, depends in the first instance on the collection and analysis of good facts. Particularly in a scientifically sophisticated field such as life-sustaining technologies, therefore, courts look carefully and respectfully to the clinicians most directly involved in a patient's care to inform the legal process concerning relevant clinical facts about the patient's condition and prognosis. Courts use provider-supplied clinical data as the basic building blocks upon which legal rules and social policy are constructed, as the legal process strives to draw legally and ethically meaningful analogies and distinctions among cases presenting different facts. Some of the most recent judicial decisions have been well-publicized as inconsistencies — for example, the purportedly conflicting results in the Bartling (Bartling v. Superior Court, 1984b; see Scherer, 1985; Lo, 1986) and Bouvia (Elizabeth Bouvia v. County of Riverside, 1984) cases, both of which involved a competent adult, and the inconsistent legal outcomes between the Barber (Barber and Nejdl v. Superior

Court, 1983) case and the Conroy (In re Conroy, 1983) intermediate appellate decision (which many overlook was later reversed on appeal) (In re Conroy, 1985; see Cantor, 1985; Curran, 1985), both of which involved withdrawal of tube feeding from an incompetent person. But these may be due not to the respective courts being ignorant of the clinical realities, but precisely to those courts being attuned to the differing physical and mental conditions of the involved patients and the different types of proposed medical interventions (Annas, 1983).

One illustration of the use of clinical data in judicial decisionmaking is the way that courts handle the highly controversial "quality of life" issue. Courts that have considered this issue have unanimously rejected the concept as a valid criterion in treatment decisionmaking for an incompetent patient, maintaining that each person's life is of infinite worth. However, most judicial opinions in this area implicitly consider this factor anyway, but in the guise of the patient's "persistent vegetative state" (In re Quinlan, 1976) or irreversible absence of cognition or sapience. In other words, the same issue is framed in medical, rather than moral, terms, for psychological reasons. Regardless of how the issue is described, the courts need and use clinical data in order to arrive at just, humane conclusions.

The problem faced by the courts here is the same as that encountered by clinicians, patients, and families — namely, good facts upon which to build good law and good ethics may at times be exceedingly difficult to obtain. Making and communicating diagnoses and prognoses in the context of life-sustaining technologies is frequently an uncertain and imprecise process more dependent on art than on science (Meier and Cassel, 1983; Lo, 1984; Billings, 1985) and incapable of giving the courts clear and unequivocal facts for their decisions. Nonetheless, courts faced with difficult decisions concerning the care of critically ill patients uniformly turn to clinicians for an account of the clinical data to be considered in fashioning sound remedies and rules.

Beyond the evolving law's general consistency with such clinical data as are available, there also appears to be a strong congruency between the great bulk of published legal opinions and the emerging (although not unanimous) ethical consensus (see discussion of voluntary guidelines later in this paper) on issues concerning life-sustaining technologies. The ethical emphasis on patient autonomy and self-determination in medical decisionmaking is at the heart of every judicial decision in this area, as courts have held that the right to make decisions about one's own medical care is embodied in both the common law right to bodily integrity and the constitutional right to privacy (and, in some cases, in the constitutional protection of religious freedom as well). Except for a few cases where the interests of third parties were deemed compelling (John F. Kennedy Memorial Hospital v. Heston, 1971), the courts have consistently ruled that mentally competent adults possess the right to decline even life-saving medical interventions, while the autonomy of incompetent patients has been safeguarded by application of the "substituted judgment" test that asks what the individual would have wanted if personally capable of deciding. There is nothing unsound, unreasonable, or unethical about this legal approach.

Procedurally, the courts (e.g., Matter of Spring, 1980; Leach v. Akron General Medical Center, 1980; Severns v. Wilmington Medical Center, Inc., 1980) have overwhelmingly — with the notable exceptions of the Saikewicz case, which was severely limited by subsequent Massachusetts decisions (Matter of Spring, 1980), and of the Eichner and Storar cases from New York, which allow for no substitute decisionmakers — recognized and encouraged the vital role of family members and attending clinicians in exercising an incompetent patient's rights on his or her behalf. (On the importance, including the legal value, of encouraging family involvement in medical decisionmaking for an incompetent patient, see Brody, 1985; Erstling, 1985; Sherlock and Dingus, 1985; see also Ad Hoc Committee on Medical Ethics, 1984, on why the family has no legal status in decisionmaking when the patient is competent.)

Substantively, the judiciary has adopted guidelines for the surrogate exercise of such rights according to the generally endorsed ethical principle of proportionality or benefit/burden ratio. It cannot credibly be claimed that these legal developments constrain desirable decisionmaking concerning life-sustaining technologies or that they compel the opposite, although cases like Saikewicz, Eichner, and Storar do foster the medical profession's impression of the law as inconsistent and complex.

In addition, the law affirmatively encourages, and in an increasing number of States expressly enables, cooperation and collaboration among patient, family, and caregivers in a process of advance health care planning designed to avoid many of the difficult and emotion-laden dilemmas that arise in critical care medicine where adequate advance planning has not occurred. Most deaths today happen in health care institutions and a majority of these deaths are expected by physicians (Tolle, et al., 1985). Legal enablement of advance health planning takes the form of legislative and/or judicial recognition of legal instruments such as living wills and durable powers of attorney to effectuate the wishes of a once-competent patient in the event of subsequent incompetence (see President's Commission, 1983; Kapp and Bigot, 1985). Again, such legal developments are well in line with the weight of current professional judgment, ethical analysis, and public opinion.

The Myth of Inflexibility

The common lament that legal requirements are too simpleminded, rigid, and inflexible to accommodate easily to clinical realities and contingencies is the flip side of the previously discussed myth that the law is too ambiguous and nondefinitive to provide sufficient guidance to participants involved in decisions concerning life-sustaining technologies. The inflexibility myth misjudges both the intent and the effect of the law in general, and in this sphere particularly.

It is true that legal rules that are too rigidly and inflexibly drawn and interpreted will necessarily fail, for at least two reasons. First, it is not humanly possible for a lawmaking body (or a medical professional) to anticipate all contingencies that might arise concerning life-sustaining technologies (or any other matter) and to draft definitive laws comprehensive enough to directly cover them. Any attempt to do so would impose unnecessary constraints without corresponding benefits. Second, excessively inflexible legal requirements erode the exercise of discretion and judgment by the actors, and thus impinge on the autonomy of patient and family and on the professionalism of the caregivers. It is by asking for cut-and-dried, risk-free legal answers that medical professionals risk forfeiting their ethical and clinical freedom (Whiteneck, 1985).

Legislators and jurists are cognizant of these inherent limitations of the law. What is developing, therefore, is the legal setting of broad boundaries, beyond which lies conduct that most people would agree is unacceptable, but within which the participants are afforded substantial leeway to exercise judgment and discretion based on personal values and aspirations (President's Commission, 1983). For medical professionals, the crux is not to curse the law for manufactured defects, but rather to know its limits and to acknowledge and embrace the discretion that the law permits and even promotes among medical professionals, patients, and families. While it is the role of law to establish societal rules, it is ordinarily the physician's role, in consultation with patient and family, to apply society's rules to particular circumstances.

The Myth of Lethargy

The final myth explored in this paper is the claim that the law is too slow and lethargic in responding to emerging clinical controversies. This is the mirror image of the complaint that the legal system is too anxious and quick to gratuitously intrude into private, personal matters. Many who eagerly criticize the ubiquitous presence and expanding role of attorneys in contemporary society are the same persons who shout that "there ought to be a law" as a means to "escape from [the] freedom" (Fromm, 1941) that is imposed by the awesome responsibility to exercise judgment and discretion in life-and-death affairs. It is a paradox that no one wants to be told what to do, but everyone desires the security that comes with clear presciptions and proscriptions.

The law does react slowly to emerging clinical controversies, but this is not a sign of lethargy. Rather, it is (at least ideally) an indication of deliberation and care. Such a methodically paced process is more likely to produce better legal outcomes, allowing for a greater opportunity to gather evidence, hear arguments from interested parties, and engage in more thoughtful analysis of and reflections about competing points and perspectives (Siegler and Weisbard, 1985). Too, the law generally attains a larger degree of public acceptance and respect when it follows and codifies a widespread ethical consensus on a sensitive issue. Problems with public respect for the law often arise when the law makes the error of moving out ahead of the general community too far and too fast in the absence of substantial ethical agreement. We can avoid or minimize the harm of this happening in the realm of life-sustaining technologies by withholding criticism of the law for patiently and cautiously embodying, rather than trying to anticipate, the growing ethical consensus surrounding the delivery or termination of various types of medical care to critically ill persons. The law must react when needed, not preempt merely for the sake of activity.

One further point is in order. While the law is properly deliberate in developing broad rules and policies, expeditious hearings to apply the rules to particular patients can frequently be obtained. For example, hospital attorneys are adept at getting emergency court orders authorizing treatment for incompetent patients or minors.

INFLUENCE OF MEDICAL DECISIONS ON PERCEPTIONS ABOUT THE LAW

Physicians' Responses to Perceptions of the Law

Because of their fears and uncertainty about the law, physicians sometimes make decisions out of public view. They may attempt to avoid justifying or documenting decisions. In a study of DNR orders in San Francisco, physicians in 4 of the 136 cases studied gave oral orders to nurses not to resuscitate patients in case of cardiopulmonary arrest, but purposely did not write the orders in the medical records. In these four cases, the physicians disagreed with the families of incompetent patients about the decisions (Lo, et al., 1985).

In six cases, the physicians gave "limited," "slow," or "partial" code orders (Lo, et al., 1985). These orders meant that basic cardiopulmonary resuscitation would be started, but that advanced cardiac life support, such as intubation and mechanical ventilation, would be withheld. Again, these decisions generally were used in cases of disagreement with patients or families. Such limited or oral orders may cause confusion, however, and create legal jeopardy for nurses. In addition, they greatly decrease the likelihood of successful resuscitation. Limited attempts at resuscitation may seek to convince the family that "everything was done." But they provide no benefit to the patient and cause cynicism among the nursing and medical staff (Lo and Steinbrook, 1983). Thus they cannot be justified, unless the patient agrees with them.

Physicians may believe that their risk of liability is decreased if they do not give written orders or discuss their decisions in the medical records. This belief is unsound risk management policy. Moreover, it violates the ethical ideal that difficult decisions should be made openly and justified.

Another effect of these perceptions about the law is that life-sustaining treatment may be continued on incompetent patients, whether or not it is medically or ethically appropriate. After the Saikewicz case in Massachusetts, many incompetent patients had life-sustaining treatment applied or continued. One expert in health law described a dying woman who was resuscitated 70 times in a 24-hour period, a brain-dead patient in whom placement of a cardiac pacemaker was planned, and family members who had to bar the door of a patient's room to prevent resuscitation (Annas, 1982). In all cases, the treatment was recommended by hospital counsel. The expert wrote, "Physicians should know at least enough law to be able to tell when the advice their lawyers are giving them is so incredible that it is most likely wrong" (Annas, 1982).

Similarly, while Drs. Barber and Nejdl faced criminal charges for discontinuing intravenous fluids on a comatose patient, many physicians in California were reluctant to discontinue any life-sustaining treatment on incompetent patients. An expert in bioethics said that the prosecution created "terror" among physicians who must decide about life-sustaining treatment for comatose patients (Rohrlich, 1983). He cited a case in which physicians refused to disconnect a ventilator from a brain-dead patient, even though this procedure is expressly permitted by California law (and the law of most other States as well).

There are several reasons why physicians generally are less concerned about legal jeopardy for continuing life-sustaining treatment over objections than they are about legal liability for withholding life-sustaining treatment. Hospital administrators similarly seem less concerned about the legal risks of continuing life-sustaining treatment, as discussed earlier. Court proceedings initiated by patients and families to require physicians to withhold or withdraw life-sustaining treatment have not generated much adverse publicity for the physicians. Similarly, the possibility of civil malpractice actions seems remote and unlikely to stigmatize physicians. The public seems willing to accept physicians' justification that in questionable or doubtful cases, they should continue life-sustaining treatment rather than allow a patient to die.

Physicians' perceptions of the law may also cause them to practice defensive medicine. They may order additional tests or follow-up visits. The American Medical Association claims that defensive medicine may be costing as much as $24 billion a year (AMA Special Task Force on Professional Liability and Insurance, 1985). But it is difficult to define defensive medicine exactly: "Does the term cover all tests and procedures, however medically defensible, if the principal motivation of the provider in calling for these measures is a fear of litigation? Or, does it, rather, encompass only measures which have no medical justification and thus, are undertaken solely to guard against legal liability?" (Rosoff, 1985). Moreover, there are little good data on the scope of defensive medicine. One 1980 study reported that medicolegal considerations are a contributing factor in only 1 percent of all test orders (Wertman, et al., 1980).

Inconsistencies Between Law and Medical Practice

Medical practice is inconsistent with the law in fundamental ways. For example, clinical assessment of whether a patient is mentally incompetent may differ markedly from legal requirements. Strictly speaking, competence is a legal concept. An adult person is presumed to be competent until the courts declare that person incompetent and appoint a guardian. But in medical practice such legal proceedings are rarely initiated. Instead, if an elderly person is deemed incompetent by caregivers, family members are usually asked to make decisions on behalf of the patient. It is not clear why clinical practice so diverges from legal standards. Physicians may be ignorant about the precise legal definition of competency or may regard legal proceedings as too cumbersome and time-consuming, with insufficient benefits to justify the costs.

The danger of such informal assessments of competency is that elderly patients may be inappropriately denied control over decisions about their medical care. This possibility is especially worrisome because caregivers may apply standards of competency that are quite different than the legal ones. While there are no rigorous studies on the issue, often these assessments of competency are based on the mental status examination, which tests whether the patient is oriented, has intact memory, and can perform simple calculations. If there is a question about a patient's competence, it is far more likely that a psychiatrist will be asked to see the patient and do a more elaborate mental status test than that the courts will be asked to settle the question. But using the mental status test to assess competency may be inappropriate. From a legal and ethical perspective, the correct standard for incompetence is that the patient is unable to comprehend the nature of the tests or treatment, the risks and benefits, the alternatives, and the likely consequences of his or her decision.

A fundamental question is who should make decisions for incompetent patients about life-sustaining treatment. As discussed in the other papers in this volume, the competent patient should make decisions. If the patient is incompetent, a representative of the patient should decide. The presumption is that the family of an incompetent patient should make decisions. In some cases, it is appropriate for the courts to appoint a legal guardian.

Medical practice, however, may be inconsistent with this standard; patients and families often are not involved in decisions about life-sustaining treatment. The study of DNR orders in three San Francisco teaching hospitals illustrates this problem. DNR orders had been considered in 136 of 3,282 patients admitted to the medical services; 18 percent of competent patients did not participate in such decisions. Reasons given by physicians for not involving patients in decisions were family requests that the patient not be involved and the belief that the patients' wishes were already known (Lo, et al., 1985). Physicians are unable to determine accurately patient preferences about resuscitation, however, without asking them directly (Bedell and Delbanco, 1984). Similarly, in two other studies of DNR orders, 18 to 20 percent of competent patients did not participate in decisionmaking (Evans and Brody, 1985).

When patients are considered incompetent, families often do not participate in decisions. In the study of DNR orders in San Francisco, families of incompetent patients participated in decisions in only 81 percent of the cases. Physicians' reasons for not involving families in decisions included a fear that families would disagree with the DNR order; difficulties physicians had talking with families; the belief that medical indications were decisive; and the patient's prior request that the family not be involved (Lo, et al., 1985).

Thus, there is a significant discrepancy between legal and ethical guidelines about life-sustaining treatment and actual practice. The lack of involvement by families of incompetent patients in decisions is particularly worrisome because the courts are also not involved in these decisions. In the San Francisco study, the courts were not involved in any of the 136 cases in which DNR orders were considered, even though patients were regarded as incompetent in 56 percent of the cases (Lo, et al, 1985).

In some situations, the courts may not need to appoint a guardian to make such decisions regarding incompetent patients. Specifically, several courts have ruled that guardianship proceedings are not required if the patient is in a persistent vegetative state, and if all family members and the physician agree with the decision. It seems that it might be prudent to go to court if there is no family or if family members disagree among themselves or with the physician. (For further discussion of these situations, see the other papers in this volume.)

Once again, medical practice may not be consistent with these legal and ethical recommendations. In the study of DNR orders in San Francisco, 20 cases involving incompetent patients fit these standards for judicial review (Lo, et al., 1985). In 12 cases, the patient was incompetent and there was no family. In 4 cases, the family disagreed with the physician, and in 2 other cases, the family members could not agree among themselves. Thus in 20 of 3,282 hospital admissions to the medical service (0.6 percent), ethical and legal guidelines would recommend involving the courts. This did not happen, however. Instead, physicians made decisions unilaterally in these cases and in no case was the physician charged with civil or criminal liability. Although it is not clear why these cases were not taken to court, physician concerns about the delays in the legal system probably were an important factor.

Another inconsistency is that certain distinctions traditionally made in the law are not accepted in medical practice. The distinction between stopping treatment and not starting it troubles many caregivers, even though philosophers have argued that there is no significant moral difference (Burt, 1981; Lo, 1986). A reason that justifies not starting a treatment also justifies stopping it. Moreover, accepting this distinction may have unintended and undesirable consequences. Caregivers may be reluctant to initiate a potentially useful treatment because they fear that they will have to continue it indefinitely. Recent court decisions also have rejected this distinction (Barber v. Superior Court of the State of California, 1983; In the Matter of Claire C. Conroy, 1985).

Ironically, arguments to discontinue treatment may be more compelling than arguments not to initiate treatment. If a treatment has been started and proved unsuccessful, it can be discontinued because it provides no medical benefit to the patient. However, caregivers often are reluctant to discontinue life-sustaining treatment, even though they would not start the treatment under similar circumstances. They may even feel that stopping treatment is a direct action that kills the patient.

A 1983 case in Washington, DC, illustrates the reluctance of caregivers to discontinue treatment (Weiser, 1984). Nurses in the intensive care unit felt uncomfortable discontinuing the ventilator from a young patient whose coma was judged irreversible by the attending physicians and whose family wanted treatment discontinued. The nurses refused to physically discontinue the ventilator; their disagreement required the chief of medicine and the chief of nursing to intervene in the case. After an emergency weekend meeting, the attending physician himself had to disconnect the ventilator. Similarly, caregivers may be reluctant to discontinue intravenous fluids or tube feedings once they have been started.

The distinction between ordinary and extraordinary care illustrates another difference between clinical practice and law. Clinicians commonly refer to expensive, highly technological, unusual, or experimental treatments, such as artificial hearts, as extraordinary or heroic. In contrast, simpler, more common treatments like intravenous fluids may be considered ordinary care. Recent court decisions have rejected this distinction (Jonsen, 1984). In agreement with philosophical arguments, the courts have ruled that all treatments may have both therapeutic effects and side effects. If the burdens of treatment outweigh the benefits to the individual patient, then the treatment is disproportionate and not appropriate (Barber v. Superior Court of the State of California, 1983; In the Matter of Claire C. Conroy, 1985). Thus, to decide whether a treatment is appropriate we must look at the benefits and burdens to an individual patient, not at the nature of the technology. In other words, one cannot say that a ventilator is "heroic" rather than "ordinary." For some patients, like the postoperative individual, mechanical ventilation is indicated, because its benefits are far greater than the burdens. For an irreversibly comatose patient, however, the benefits of mechanical ventilation are few, and the treatment is usually not indicated.

Yet, the terms "benefits" and "burdens" are ambiguous and rarely used by clinicians. While caregivers may use the terms risks and benefits, these terms are usually applied only to medical effects and complications, such as the risk of bleeding or infection. Clinicians usually do not use "risk" to refer to loss of dignity or privacy, which may be important considerations to many patients.

The belief that artificial feedings, such as through nasogastric or gastrostomy tubes, are "ordinary" care is particularly persistent (Callahan, 1983; Lo and Dornbrand, 1984; Dresser, 1985; Meyers, 1985; Siegler, 1985). Some caregivers may consider feeding to be basic, humane care, like a warm, clean bed, that must always be given. Undoubtedly feeding has emotional and symbolic significance as nourishment and affection. Some writers acknowledge philosophical arguments against regarding feeding as ordinary care but are reluctant to withhold artificial feeding on a wide scale (Siegler, 1985). However, as noted earlier, the courts have rejected the claim that feeding is ordinary care (Barber v. Superior Court of the State of California, 1983; In the Matter of Claire C. Conroy, 1985; see also Dresser, 1985; Meyers, 1985). For each patient, the burdens and benefits of artificial feedings must be weighed. Like any other medical intervention, feedings by nasogastric or gastrostomy tubes or intravenous lines may cause complications. Moreover, for patients with severe dementia or irreversible coma, the benefits may be slim (Lo and Dornbrand, 1984).

Another inconsistency between law and medical practice is in the use of ambiguous phrases or slogans (Jonsen, et al., 1982; President's Commission, 1983). These terms cause confusion and misunderstanding because physicians and the law may use them in different ways, or there may be no explicit definition.

The term "terminal illness" presents many problems. As mentioned already, the definition of terminal illness adopted by Medicare (6 months' survival) may be impractical because physicians cannot predict a prognosis accurately. There are also more fundamental problems with this term. The Medicare definition is arbitrary and may not be accepted by many caregivers or patients. Some people may consider a person who is expected to live 6 months terminal, while others may regard a patient as terminal only when survival is expected to be 1 month or 1 week. Some physicians consider patients terminally ill only when they are moribund and will die in a few days no matter what treatment is given. Some people may consider a patient terminal when cancer is first diagnosed, while others apply this label only after metastases develop or a relapse occurs after treatment.

Although the phrase "terminal illness" is often used in living will, it is usually not defined. Under the California law, for example, two physicians must certify that the patient is terminal, but the criteria for such certification are not specified. Reasonable people may disagree on these interpretations. For living wills, the most important interpretation may be that of the patient. A patient who feels that life is valuable may not regard himself or herself as terminally ill, although others do.

POLICY ISSUES

Alternatives to Court

Because of problems with asking the courts routinely to decide cases involving life-sustaining treatment for patients who are incompetent, policies that permit alternatives to court would be useful. (For a review of the two main alternatives, living wills and durable powers of attorney for health care, see the paper by Annas and Glantz in this volume.)

Other alternatives to the courts for resolving disagreements over life-sustaining treatment for incompetent patients include institutional ethics committees, proposed as forums for discussing difficult cases and for resolving disagreements between caregivers and families of incompetent patients (Cranford and Doudera, 1984; Fost and Cranford, 1985). Among other functions, ethics committees may review and make recommendations. However, there are many unanswered questions about them. There is no evidence that ethics committees are effective in resolving disagreements or that their recommendations are consistent with ethical guidelines. Recommendations by a majority of a committee need not necessarily be consistent with the ethical and legal principles of following the preferences or best interests of patients.

Moreover, important procedural questions need to be answered, such as who may bring cases to the committee and whether patients may be represented before the committee. Although little is known about how ethics committees currently function, some may not adequately protect the interests of patients. In a 1982 survey, only 25 percent of ethics committees that reviewed cases allowed patients to bring cases to the committees. Only 19 percent allowed patients to attend committee meetings and 44 percent allowed families to do so. Limiting access to ethics committees, however, may cause patients or families to object that decisions about their medical care are being made without their participation.

The legal status of ethics committees is uncertain, although many legal experts feel that advice from an ethics committee may help caregivers in the courts. Seeking consultation with an ethics committee may demonstrate that the caregivers were willing to discuss decisions openly and to follow ethical principles agreed upon. The Torres case in Minnesota illustrates how the legal status of ethics committees needs to be clarified (In the Matter of the Conservationship of Rudolfo Torres, 1984). Torres was in a persistent vegetative state following cardiopulmonary arrest. The appeal questioned whether a court-appointed conservator could authorize removal of his ventilator. Evidence introduced indicated that three area ethics committees would favor removal of the ventilator. The hospital hoped that such evidence would establish a community standard for appropriate decisionmaking and treatment for such patients. The Minnesota Supreme Court affirmed a lower court ruling allowing removal of the ventilator. The decision affirmed that a court order was not necessary in this case but did not comment on how ethics committees might serve a positive role in such cases. Thus, it remains unclear how ethics committees might avoid court involvement or delays.

Another alternative to regular court involvement exists. In response, at least in part, to the perception and fear of legal intrusion into medical matters, a number of voluntary (i.e., nongovernmental) guidelines for decisionmaking concerning life-sustaining technologies have been developed. These voluntary guidelines take a number of different forms: statements by official professional organizations (e.g., JAMA, 1980; American Geriatrics Society, 1985; JAMA, 1985) and by ad hoc groups of individuals (Concern for Dying, 1983; Wanzer, et al., 1984; Smith and Bodai, 1985), which sometimes have an interdisciplinary composition (e.g., Hoyt and Davies, 1984; Task Force on Supportive Care, 1984; Crawshaw, et al., 1985); statements on the broad area of life-sustaining technologies (e.g., Wanzer, et al., 1984) or with a narrower concentration, usually DNR orders or artificial feeding (President's Commission, 1983, p. 493; Evans and Brody, 1985; Miles and Crimmins, 1985); and statements that are concerned with substantive principles alone (e.g., Miles and Ryden, 1985), with procedures alone (e.g., President's Commission, 1983, pp. 439-442), or with a combination of the two (e.g., President's Commission, 1983, pp. 501-505).

There is another way to characterize voluntary guidelines in this area. A distinction may be drawn between voluntary guidelines that attempt to codify and restate current law, on one hand, and those guidelines that consciously go beyond (but not necessarily in opposition to) existing law, and therefore attempt to stimulate (rather than quell) legal debate and influence the development (or the clarification and precision) of the law, on the other hand.

Most voluntary guidelines fall within the first category, as attempts to codify and restate the group's understanding of current legal boundaries (e.g., Ad Hoc Committee on Medical Ethics, 1984). It is widely accepted, and experience appears to confirm, that institutional adoption of guidelines concerning the use of life-sustaining technologies can protect the health care institution and involved professionals from legal liability for decisions made and actions taken in accordance with those guidelines (U.S. Congress, 1984; Evans and Brody, 1985; Miles and Crimmins, 1985; Miles and Ryden, 1985). Such policies should be clear, reasonable, and legally consistent (to the extent the jurisdiction's law can be ascertained), and implemented in a fair, good faith, documented manner. Institutions have been urged to adopt and implement such internal guidelines (Clayton, 1985; Hirsch, 1985; Miles and Ryden, 1985).

Voluntary guidelines that purposely and conservatively embody existing law are not without criticism. Cassel has warned of the danger that voluntary guidelines that too closely resemble regulations may be more motivated by risk management avoidance of lawsuit considerations (i.e., primarily economic incentives) than by concern for the patient (Cassel, 1984). She urged that guidelines be motivated by ethical convictions rather than risk management precepts, an admonition echoed by Hunter (Hunter, 1985), who argues that a policy and process that devolve to mere risk management is too one-dimensional, ignoring important ethical and emotional concerns. But, she adds, adoption and implementation of a fair, reasonable policy will — incidentally — be a good hedge as well (see also Kapp, in press). Keeney (in Childress, 1984/85) has observed that, while conservative guidelines are useful, difficult life-sustaining technology issues cannot be decided by a "cookbook" approach; rather these cases should remain hard, but not impossible.

Some voluntary guidelines consciously go beyond current legal boundaries (to the extent that they have been enunciated), for the purpose of influencing changes in the law (Lynn, 1984; Wanser, et al., 1984; Gordon and Hurowitz, 1985). The Harvard brain death criteria are an excellent example of this. There is a recognition that the law should unfold by slow evolution, following and embodying formation of an ethical consensus (U.S. Congress, 1984), and such voluntary guidelines try to promote that evolution by providing evidence of a fermenting ethical consensus.

The physician who acts in accordance with voluntary guidelines that purposely go beyond enunciated legal boundaries (e.g., by removing a feeding tube from a non-terminally ill patient in the absence of a statute or judicial decision explicitly authorizing such action in that particular jurisdiction) perhaps operates at higher legal risk than the physician who follows (and documents compliance with) voluntary guidelines that specifically track applicable statutes or court decisions. Nonetheless, there are no reported legal cases where after-the-fact liability has been alleged (much less found) against a physician or other health care provider or institution for rendering care that was inconsistent with relevant voluntary guidelines. And by fostering such guidelines, the physician may be helping to improve medical care and legal and ethical standards. Although declaratory and injunctive relief have been sought a few times against formal or ad hoc institutional policies (e.g., Bartling v. Superior Court, 1984b; Elizabeth Bouvia v. County of Riverside, 1984), arguably the existence of such policies allowed disagreements to be resolved prospectively, rather than retrospectively through malpractice suits for damages.

Potential for Federal Legislation

The President's Commission observed that "very little attention has been given to providing programmatic incentives for good decisionmaking practices or disincentives against inadequate ones" (1983). There may be a role for legislation in molding those incentives, especially in light of many court decisions that urge boundary setting by the legislature as preferable to broad precedent announcements by the judiciary (Barber and Nejdl v. Superior Court, 1983; In re Conroy, 1985). It may be possible for legislation to narrow the gap between legal perceptions and medical decisionmaking, and thus positively contribute to more humane and sensible use of life-sustaining technologies.

Mechanisms for Action

For the Congress, there are two types of action that can be taken: direct command and control requirements, and requirements tied to financing.

Congress could enact direct command and control requirements governing medical care that is both directly financed and provided by the Federal Government. This would include medical care provided through the military, Veterans' Administration, Public Health Service, and Indian Health Service.

For non-Federal health care institutions, Federal attempts to control medical practice through direct command and control regulation would be problematic from both a legal and a policy viewpoint. Legally, the regulation of medical practice has traditionally been considered a power constitutionally reserved to the States (e.g., professional licensure and discipline, definition of medical malpractice standards and informed consent requirements, delineation of physician/patient confidentiality, or determination of patient competency). Congress would be hard-pressed to persuasively cite Constitutional authority empowering direct Federal intrusion into medical practice via straight command and control requirements.

Direct Federal command and control requirements are also inadvisable as a policy matter. Some degree of uniformity across jurisdictions is desirable, both to alleviate part of the anxiety created by inconsistencies among jurisdictions and to deal with potentially troubling conflict of law situations. (For example, when an Indiana citizen executes a durable power of attorney naming a son in Ohio as attorney-in-fact, but then become terminally ill in Florida, the law of which jurisdiction applies?) However, notwithstanding this need for uniformity, individual States should still be given substantial room for innovation and experimentation in testing different approaches to the diverse issues raised by life-sustaining technologies, so that out of these State laboratories we may distill the most successful answers.

Federal legislation tied to Federal health care financing, under Congress' Constitutional taxing and spending power, is a more appropriate mechanism for the Federal Government to use to influence decisionmaking concerning life-sustaining technologies. In contrast to direct command and control requirements, such legislation could create strong economic and political incentives encouraging action, by attaching certain conditions or strings to the receipt of health care dollars under certain categorical Federal programs (e.g., Medicare, Medicaid, CHAMPUS, or elder abuse grants). Since the recipients of Federal health dollars are diverse, legislatively created incentives encouraging specific action could be aimed at States, at individual medical professionals and health care institutions, and at private institutions and organizations.

Examples of Legislation

Federally enacted incentives for specific action could take a variety of forms. The eight examples here are intended to be illustrative to provoke discussion only; they are by no means comprehensive, and no particular endorsement or disavowal should be inferred.

Federal legislation might require, as a condition of State receipt of Federal health dollars (e.g., by attaching to Medicaid grants), that each State enact a natural death or living will statute. Either a single model could be specified (such models currently exist; see National Conference of Commissioners on Uniform State Laws, 1985) or each State could develop its own unique statute. Thirty-six States have already done so. The conflict of laws problem could be addressed by requiring each State to include a provision honoring living wills validly executed in another State. Several living will statutes contain such a reciprocity provision (e.g., Maine Rev. Stat. Ann. Title 22, ch. 710-A, sect. 2930; Maryland Health General Code Ann. sect. 5-612), which treats the living will no differently than any other kind of contract.

Federal legislation might require, as a condition of State receipt of Federal health dollars, that each State enact a durable power of attorney for health care statute. Again, either a single model (Uniform Durable Power of Attorney Act, 1982) or individual State experimentation could be encouraged, and a mandatory reciprocity requirement could be imposed to deal with the conflict of laws issue.

Federal legislation might create incentives for the setting up of Institutional Ethics Committees (IECs) (Cranford and Doudera, 1984). This could be accomplished either by conditioning State receipt of Federal health dollars on the enactment of State statutes mandating that health care institutions set up such committees, or by directly conditioning a health care institution's receipt of Federal dollars upon its establishment of an IEC. The Model Infant Care Review Committee (50 FR 14893-14901) found in the Federal "Baby Doe" regulations protecting handicapped newborns against discrimination in medical care might be a source of guidance in this regard, with appropriate modifications to reflect geriatric concerns. Although attracting substantial criticism, the final version of these regulations represents the political compromise of diverse professional and advocacy interest groups, and affected institutions have thus far experienced little difficulty in living with these regulations.

Federal legislation already requires health care institutions, as a condition of the receipt of Medicare funds, to have contracts with federally approved statewide Peer Review Organizations (PROs) (Mihalski, 1984) to review the necessity, appropriateness, and quality of medical care provided to Medicare beneficiaries. The legislation creating PROs could be amended to expand the role of these bodies and involve them in prospective, concurrent, and retrospective review of cases raising legal and ethical life-sustaining technology issues, with reimbursement for the care of individual patients dependent upon satisfactory handling of those issues.

Federal legislation could condition State receipt of Federal domestic violence or elder abuse grant dollars on enactment or amendment of an elder abuse and neglect statute that clarifies issues of liability either for withholding or withdrawing life-sustaining treatment, on one hand, or for treating against the patient's wishes, on the other, under that State's criminal and civil law. Such statutes could be encouraged on a uniform basis, on a completely individualized basis, or on an individualized basis within specified Federal boundaries. Again, one model might be the Federal "Baby Doe" legislation (Public Law 98-457) and regulations (50 FR 14878-14892), which tie protection of handicapped newborns into each State's existing child abuse and neglect system and which purport to strike a balance between the sanctity of life and the recognition that in some circumstances medical care may be so futile or disproportionately burdensome as to be nonobligatory. (The regulations specifically disclaim applicability to adult patients, but there is no logical reason they could not be adapted to adults.)

The value of voluntary, privately derived guidelines regarding the use of life-sustaining technologies was discussed earlier. Federal legislation could create grant programs to fund private groups, especially professional associations, to develop and disseminate applicable policies among medical professionals.

Probably the greatest single need in this area is for education of medical and legal professionals regarding the legal, ethical, and economic issues involved in decisionmaking concerning life-sustaining technologies. Federal legislation could create grant programs to fund medical schools, law schools, health care institutions, and professional associations to develop and implement educational programs for the teaching of health law, medical ethics, and medical economics to medical students, medical residents, practicing physicians, law students, practicing lawyers, and judges, with special emphasis on life-sustaining technology issues.

Federal legislation could create grant programs to fund educational institutions, professional associations, health care institutions, and other private groups for special research and demonstration projects designed to address the issues raised in this paper.

Policy Arguments Regarding Federal Involvement

As these suggested strategies indicate, a number of mechanisms exist for Federal involvement in attempting to reconcile legal perceptions and medical decisionmaking concerning life-sustaining technologies. There are both advantages and disadvantages of such involvement.

One advantage of Federal involvement might be the opportunity for a clarification of the applicable substantive and procedural law. Removing medical professionals' doubt, ambiguity, and distrust of the law should lead to better substantive decisions and to decisionmaking processes that are more just. Clarification of the law should lead to greater confidence by medical professionals, and should make resort to the courts for advance legal prophylaxis an even less common occurrence than it is presently.

Federal involvement could produce uniformity in the law, which would alleviate confusion and counterproductive action engendered by current inconsistencies among jurisdictions. Even if uniformity is not achieved, Federal legislation could encourage reciprocity among States, so that, for example, there would be no doubt (for patient, family, or medical professional) regarding the legal validity of an advance directive executed in State A by a patient who becomes critically ill in State B.

In the area of grants for policy formulation, education, and other research and demonstration projects, the Federal Government is an appropriate source of funding and of delineation of its goals and objectives. Finally, to the extent that tension between legal perceptions and medical decisionmaking exists and exerts a negative influence over medical care, particularly care involving life-sustaining technologies for the Nation's elderly citizens, both the public and the medical profession look to the Federal Government as a source of legal and moral leadership to help resolve that tension and to facilitate more humane and rational care of the elderly.

There are also counterarguments to Federal involvement at this time. As noted earlier, it may be best to wait for definitive legal enactments until society has reached consensus on the ethical stance regarding life-sustaining technologies. Although such a consensus appears to be forming, arguably we are not at the point yet where it has been adequately achieved.

As also noted above, uniformity in the law may stifle State and institutional experimentation with different approaches to these complex issues -- experimentation from which valuable ideas and models may eventually emerge. A plurality of approaches, at least at this relatively early stage of grappling with these issues, may be preferable to mandating a single model.

New grant programs may unduly burden an already strained Federal budget. Although the potential benefits of funding efforts in policy formulation and professional education are obvious, these benefits may not exceed the pressing current need to control Federal expenditures.

The role the Federal Government could play in addressing the tension that now exists between legal perceptions and medical decisionmaking regarding life-sustaining technologies deserves further thought and discussion. Federal activity can best take the form of encouraging individual States, health care institutions, and professional associations to address the difficult issues raised and to devise innovative policies and mechanisms for resolving those issues. This paper suggests a number of potential avenues of Federal involvement that are consistent with this philosophy.

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PHILOSOPHICAL ISSUES CONCERNING THE RIGHTS OF PATIENTS SUFFERING SERIOUS PERMANENT DEMENTIA

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PHILOSOPHICAL ISSUES CONCERNING THE RIGHTS OF PATIENTS SUFFERING SERIOUS PERMANENT DEMENTIA

I. Introduction

A. Dementia

This is an essay about the rights of seriously and permanently demented people. Is some minimum level of mental competence, which the demented cannot reach, essential to having any rights at all? If demented people do have rights, do they have the same rights as normally competent people, or are their rights altered or diminished or extended in some way in virtue of their disease? Do they, for example, have the same rights to autonomy, to the beneficence of their custodians, to dignity, and to a minimum level of resources as sick people of normal mental competence have? These are complex questions, and will require an extended analysis of various philosophical issues.

My emphasis will be on these philosophical issues. I shall not consider, except in passing, the present structure of legal rights and other provision for the demented, or the present practices of doctors and other custodians or officials who are charged with their care. These are the subjects of other papers prepared for the Office of Technology Assessment as part of its overall project on senile dementia, and though I have read several of these, and taken account of them in considering the issues I discuss, I make no effort to summarize or repeat their content. Nor shall I attempt any comprehensive report of the behavior, detailed capacities, physiological characteristics, prognosis or treatment of demented people. These, too, are the subjects of other papers in the overall project, several of which I have read and relied on.

I must, however, make plain the circumstances of dementia assumed in my various arguments and conclusions. I am considering what I several times call serious dementia. I mean the situation of patients who have lost substantially all memory of their earlier, competent lives, who cannot, except periodically and in only a fragmented way, recognize or respond to other people to whom they were formerly close, who are incapable of sustaining plans or projects or desires of even basic or simple structure, and who cannot themselves attend to or appreciate their own simple needs of nourishment and cleanliness. I am also considering what I call permanent dementia. I mean the condition of patients whose dementia is based in physiological deterioration that cannot, with presently conceivable medical technology, be reversed to a point at which serious dementia would disappear. Since dementia is normally a progressive disease, there are stages of dementia, and my various arguments apply, with full force, only to the very late stages I call serious and permanent. I believe that it is crucial to decide what rights people retain or have in that tragic condition in order to consider the different and in some ways more tractable question what rights they have in earlier stages on the road towards it. But this essay is only about the rights of the people I describe.

B. Rights as Trumps

Many of the rights I consider are in one way or another political rights: rights people may or may not have that their community as a whole treat them, or arrange for their treatment, in specified ways. I understand political rights in the way suggested by a metaphor: that rights are trumps. The normal, general responsibility of legislators and other political officials, in the United States and in other Western democracies, is to improve the "general welfare," or the "public interest"; to work, that is, for the "collective good" of the community as a whole. This collective good is normally understood in a roughly utilitarian way. Political decisions advance the collective good, that is, when they improve the average individual welfare throughout the political community as a whole. Any decision is likely to benefit some people and put others at a disadvantage; these gains and losses must be traded off to decide whether the decision is in the interest of the community as a whole by seeing whether gains outweigh losses, and so improve the average welfare, or vice versa.[1]

Individual rights act as trumps over these calculations of collective welfare, in the following way. If a community recognizes an individual right, it recognizes that it would be wrong to disadvantage particular individuals by violating that right even though that decision would be in the general interest. It is widely accepted, for example, that people who are seriously ill have a right to a certain level of medical care whether they can afford it or not. That means they are entitled to that care even though it would serve the general welfare of the community best by denying it to them. This essay considers whether even people who are demented should be understood to have rights that act as a trump over the general welfare in that way, and, if so, what these rights are.

C. Demented and Past Selves

A single question runs through almost all the discussion of particular rights I shall undertake, and it is helpful to identify that question, in an abstract way, at the outset. We are considering the rights, not of someone who was born and always has been demented, but of someone who was competent in the past. We may therefore think of that person, as the putative holder of rights, in two different ways: as a demented person, in which case we emphasize his present situation and capacities, or as a person who has become demented, in which case we emphasize that his dementia has occurred in the course of a larger life whose whole length must be considered in any decision about what rights he has. We shall have to face a series of problems that seem to contrast, in different ways, the interests of the person conceived in one of these two ways with his interests conceived in the other.

Does a competent person's right to autonomy include, for example, the power to dictate that life-prolonging treatment be denied him later, even if he, when demented, pleads for it? Should what is done for a demented person be in his contemporary best interests, that is, such as to make the rest of his life as pleasant or comfortable as possible? Or in the best interests of the person who has become demented, that is, such as to make his life judged as a whole a better life? (Suppose a demented patient wants care and treatment that would make him a serious burden to other members of his family, and we think that people lead better lives when they are not a serious burden to others. Is it in his best interests, overall, to allow him to become the burden he is now anxious to be? Someone's dignity seems connected, in some central way, to his capacity for self-respect. Should we care about the dignity of a dementia patient if he has no sense of his own dignity left? That seems to depend on whether the dignity of a competent person is in some way still implicated in how he is treated when he has become demented. (If it is, then we may take his former capacity for self-respect as requiring that he be treated with dignity now: we may say that dignity is necessary to show respect for his life as a whole.) Should the resources available to a demented patient depend on what his competent predecessor has actually put aside by way of insurance for his own care in that event, or at least would have put aside if insurance were available on a competitive and realistic basis. Insurance schemes, both private schemes and mandated public schemes, play an important part in the way we provide resources for catastrophes of different sorts. But is the insurance approach, as I shall call it, the proper model to use in thinking about provision for the demented? That must depend on whether a competent person has the requisite concern for himself in a later demented stage: whether he has what I shall call a prudential concern.

Many of the most prominent issues, then, about the rights of the demented, seem to call for a study of how their interests relate and connect to the interests and decisions of their past competent selves, and this connection will be a recurring theme of our discussions. But every aspect of that claim rests on an assumption I must now acknowledge: that it is correct to regard a demented person in the way I said we can, as a person who has become demented. That conception of him supposes that the competent and demented stages of his life are stages in a single life, that the competent and demented selves are parts of the same person. I relied on that assumption in the various suggestions I just made about how the interests and decisions of a competent person might affect his treatment when demented. I assumed, for example, that the control a competent person might seek to exercise over how he is treated when demented is correctly described as autonomy rather than paternalism, that is, that it is the kind of control people seek to have over the course of their own lives. I assumed, in describing the problem raised by beneficence, that it makes sense to treat the different kinds of interests I mentioned — the interest of the demented person in comfort and of the competent person in not being a burden -- as competing interests of the same person, so that someone trying to act in that person's best interests would therefore have a conflict to resolve. I raised the question whether a competent person's dignity might be still at stake when he has become demented, which would not be a possibility unless his demented stage was part of his life, and whether a competent person can have prudential concern for the demented person he becomes, which would be out of the question unless he remained the same person throughout.

Many philosophical theories about personal identity, however, challenge the assumption that identity survives serious and permanent dementia. They argue that personal identity requires psychological continuity, so that a person who becomes seriously demented, and has no important connections of memory and personality with his former self, has ceased to exist, and the demented person he has become must be treated as a new person altogether. So the question of personal identity, in this context at least, is not a mere academic philosophical issue or a barren semantic question. It must be faced, and resolved, in any competent theory about the rights of the demented. I shall postpone a detailed study of this problem, however, until the discussion, later in the essay, of the issue in which its force is most important and the matters at stake most apparent, which is the issue of whether the insurance approach is appropriate for considering the rights of demented people to resources for their care. I shall argue, there, that personal identity does survive even the most serious dementia. But I am assuming that answer to the problem of personal identity in the various arguments and conclusions, about other rights of the demented, that precede my defense of that answer. If my claims about personal identity are wrong, and identity does not survive dementia, many of these other arguments and conclusions would have to be abandoned.

II. Competence and the Domain of Rights

A. Domain and Character of Rights.

I just said that when a normal person becomes demented, we may think of him in two different ways: as someone who is demented, in which case we are attending only to his present situation, or as someone who has become demented, in which case we are surveying his whole life, his past as well as his present. The type and character of rights we recognize he has may depend, for the kinds of reasons I suggested, on which of these perspectives we believe ourselves entitled and obliged to take. In either case, however, if we claim that he now, even when demented, has interests that must be protected by rights, we are claiming a moral status for someone who is now demented: we are claiming that he now has the necessary standing to be eligible for rights. We must therefore consider, as a threshold question, whether that claim can be sound. Is some contemporary level of mental competence a necessary condition of his now having any rights at all?[2] That question asks whether competence should be taken to define the domain of rights, that is, whether only people with a certain level of mental capacity are even candidates for rights. That is a different and more fundamental question than the question whether mental competence counts in defining the character of rights: whether and how the actual rights demented people have are affected by their incapacities. We shall see that the rights of the demented are indeed different from those of other people, just because they are demented. But we must first consider the more fundamental challenge: that the demented are excluded from the domain of people who can have any rights at all.

Discussion of that question has, unfortunately, sometimes been distorted by various confusions about the concept of a "person". It is a very popular idea that only persons can have rights, and that if someone who is seriously demented is no longer a person, or fully a person, he is therefore no longer within the domain of rights. That proposition is not universally accepted: many people think animals, for example, can have rights. But it is sufficiently popular to force us to consider the claim that the demented are not persons at all. (That is, of course, not the serious question I have postponed: whether he is, in a fundamental sense, the same person he was before he became demented. If psychological continuity is a requirement of personal identity over time, then someone who becomes demented does not, in that fundamental sense, remain the same person. But it does not follow that he is not a person at all).

B. Rights and Persons.

Much of the literature of what is called "philosophical anthropology" considers the distinction between "persons" and other animals.[3] Rationality in some form has seemed, to many philosophers, essential to the distinction: hence the slogan that "man" is a rational animal. But it is perfectly consistent with that idea to insist that rationality, at most, defines the biological species of people — the species that can be rational — and that non-rational members of that species are also persons. That is the view ordinary understanding takes of the matter. We count infants as people, for example, even before they have become rational, and we can therefore count the incompetent as persons after they have ceased being rational. On this view, the connection between rationality and rights presupposed in the idea that only persons can have rights is more subtle than it might first appear. The point of rights, we might say, is to mark the special status of beings who can be (or perhaps at some point in their lives actually are) self-conscious and reflective. If so, then the demented are people who belong to the community of those eligible for rights.

Even if we decide that the main value or point of rights lies in the protection they give to actually and presently rational beings, we may still decide that securing that protection requires, as a practical matter, extending protection to beings throughout their lives who are rational only over part of that life. We can explain why infants have rights in that way: we protect the rational beings infants will become by insisting that they have, even as infants, the rights they need then to become rational beings of the right sort later, and to have the later opportunities such beings have a right to have. We can construct a parallel argument for assigning rights to the permanently demented, who will never be rational again. We might say, for example, that we protect rational beings from anxiety by assuring them that they will continue to have rights of some sort even if they become demented.

I draw, from the argument so far, only this limited conclusion: the debate of philosophical anthropology, about whether rationality is essential to personhood, is not decisive over the practical question whether the demented fall within the domain of rights. We must approach that question from closer in: we need, not a conceptual argument about what does or does not count as a person, but a moral argument about the role of competence in defining the domain of rights, an argument that begins in some thesis about the point of the institution of rights.

C. The Kantian Tradition

The Kantian tradition in moral philosophy might be thought to furnish an argument that connects competence to the moral point of rights.[4] For that tradition, the fundamental point of morality is freedom, defined as the situation of someone whose constraints are self-legislated in a metaphysical sense. Kant captured that idea in this general formulation: people should always act consistently with maxims or principles they can consistently legislate as governing the rights of everyone including themselves. This general idea suggests an important connection between morality and capacity: it suggests that morality is an institution for beings who can be free in Kant's sense, who can act on principle or in accordance with self-legislated laws. People who are seriously demented plainly lack that capacity. It is doubtful (I shall discuss the issue later) that they have autonomy at all. It might seem to follow that they are ineligible to participate in the institution of morality as Kantians understands it, and then that they can have no rights if that understanding is sound.

The first of these two steps seems correct. The demented are often capable of understanding the difference between right and wrong in what we might call a crudely behvioral way. They can, and do, make claims in the vocabulary of morality, about what ought or ought not to be done to or for them. (They seem capable, for example, of the complex emotion of resentment, an emotion that presupposes moral judgment of some kind).[5] But they are not capable of the sustained and integrated moral legislation that, in the Kantian tradition, defines freedom and gives morality its most fundamental point. The second step, however, does not follow from the first. For the question whether the demented have rights is a matter of how others should treat them; in particular it is a question of how the non-demented majority should protect them from political or personal decisions that would disadvantage them for the sake of the general welfare of that majority. The Kantian idea I have been describing has this implication: the majority should act towards the demented only in the way that each member of the majority could consistently wish everyone, including himself, to be treated if he became demented. That formulation provides no reason to exclude the demented from the domain of rights. Once we realize that the freedom in question is the freedom of those competent people whose interests can conflict with those of the demented, we can accept that the demented are themselves incapable of acting morally and still insist that they must be the objects of moral recognition.[6]

The Kantian tradition, broadly understood, includes John Rawls' famous treatise, A Theory of Justice.[7] Rawls describes the demands of justice through an expository device that is often misunderstood, and that might also wrongly be thought to suggest that the demented cannot have rights. Rawls argues that we should formulate principles of justice by asking what principles people would agree upon, as in their own "rational" best interests, if they were ignorant of all knowledge of their own background, abilities, tastes and projects. Obviously demented people are incapable of that kind of calculation. But that is no more an argument, under Rawls' theory than Kant's, that they cannot have rights. For people in Rawls' imaginary situation might ask themselves what rights they would want if, when the veil of ignorance was lifted, they discovered that they were about to become demented. Rawls has recently developed the philosophical foundations of his theory of justice more explicitly.[8] He argues that it assumes a particular political conception of human nature: not that actual people are the rational egoists presupposed in the expository device I just described, but that they have what he calls the "higher-order interests" of being both "rational" and "reasonable". But once again, even if only people like that can be the _subjects_ of his kind of morality, it does not follow that only people like that can be its _objects_. People with those higher-order interests need to ask how they should treat their demented fellow-citizens. That includes our question, whether the demented fall within the domain of rights, but it does not settle that question one way or the other.

D. The Humean Tradition.

There is a different moral tradition that we might call Humean.[9] This tradition argues that the overall point of morality is not metaphysical freedom but mutual self-interest, practical co-operation and coordination. Hume gave this simple example to illustrate the overall suggestion: conventional morality requires neighbors to help one another in need, and that requirement works ultimately for the benefit of all. Neighbors together harvest the crops of each farmer, in the right season, more effectively than if he harvested his own alone. More sophisticated illustrations are easy to find.[10] Morality so conceived seem to provide, for example, a solution to what are called "prisoner dilemma" problems. Each of us may have a reason of self-interest to dump waste into a lake running through our village, no matter whether others dump into the river or not. But if we all act on that reason each of us has, we will all be worse off because the river, and the village, will be ruined. Morality comes to our rescue: if we collectively accept a moral reason not to do what is in our individual self-interest, then we will all be better off than if we did not.[11] This mutual-self-interest picture of morality seems to sponsor the following argument for excluding the demented from the domain of rights: the domain should be limited to those who can contribute to the regime of mutual co-operation morality fosters. The demented would be free-riders in any such scheme. They cannot provide, and so would never be called upon to offer, the assistance to others that rights would guarantee for them. Nor do they have the capacity to be guided by rational morality in the way fully competent people can be guided: they are unlikely to accept, for example, that it would be immoral to pollute the village river for the kinds of reasons the Humean tradition furnishes.

We must, however, distinguish two different versions of the Humean thesis that the ultimate point of morality is mutual self-interest. These take different views of how membership in the community of those whose self-interest morality is meant to serve is fixed. On one version, membership of the moral community is fixed by principles whose purpose is itself to insure the highest average welfare within the group they select. According to that version, people are entitled to belong to the scheme of co-operation created by morality, and enjoy rights under that scheme, only so long as they can contribute to the welfare of other members, regardless of how much they have contributed in the past. For when they are unable to contribute, it would raise the average welfare within the community to exclude them from it. On the second version, membership in the moral community is fixed in accordance with some standard or standards that serve some other value or point, or reflect some other concern, than simply the concern to achieve and maintain the highest average welfare within the group they select. For example, everyone who is a member of a particular _political_ community, might automatically be regarded as a member of the moral community. _Then_ the rules and principles of the scheme are chosen so as to work in the mutual-self-interest of _that_ community, that is, of all those who are members in accordance with this independent principle. The difference between these two interpretations of the mutual interest thesis is dramatic. Under the first version, the demented have no moral standing, and so no question arises about their rights. Under the second version, the demented have rights if they satisfy the appropriate independent test for membership in the community, because then the moral rules of the community must be in their interest as well as everyone else's.[12]

The first version is barely coherent. Its basic idea -- that membership in a co-operative scheme must be limited to those who can contribute to the goals of that scheme — is appropriate only when that goal is an external one, that is, when the scheme aims at something beyond the welfare of its own members. It makes sense, for example, to suppose that a specialized military unit, or the executive board of a corporation, should be limited to those now capable of contributing to the goals of these enterprises — to commando raids or profits — and that no one should remain in such groups only as a reward for past contributions. It makes no sense, however, to suppose that membership in some organization whose goal is only the welfare of its members should be determined in order to make the welfare of the resulting group as high as possible. That treats average welfare as a commodity valuable for its own sake rather than valuable for the people whose welfare it is. It would recommend, carried to its logical extreme, a policy of murder to produce a community only of the most efficient welfare producers. We must therefore understand the Humean thesis as the second version of the idea that the point of morality is mutual self-interest. On that version, if the demented have become members of the community on whatever independent test is used, they must have rights to insure that they as well as the competent majority benefit from the community's morality.

E. The Egalitarian Tradition

I believe that the best account of the point of political rights is egalitarian. It holds that rights are required in order to enforce the underlying, fundamental principle that government must treat all members of the political community as equals, that is, with equal concern. Once again, applying that principle to the demented requires an independent judgment about whether they must be counted fully "moral citizens," that is, members of the political community to whom equal concern must be shown. If they are — if government must treat the demented with the same concern it shows to everyone else — then the demented are obviously candidates for rights. People who become demented have been moral citizens. So the crucial question becomes: is incompetence an event that terminates its victim's standing as a moral citizen of his political community?

The concept of moral citizenship figures in a great variety of political and moral issues. It plays an important role in the question, for example, of what standard the government of one community should adopt in making decisions that affect both its citizens and the citizens of other communities, in deciding on programs of foreign aid, for example, and immigration policy. The most intractable such issues, however, are issues not about how a government must treat non-citizens, to whom it owes some but less than equal concern, but about whom it should count as citizens who are entitled to equal concern. Fetuses present one such problem. (The debate about abortion often takes the form of debating whether fetuses are yet persons. It is a distinct, and perhaps more important question, however, whether fetuses are moral citizens even if they are persons, for, just as we regard foreigners as people but not citizens, it would be coherent to treat fetuses as persons who have not yet reached that standing. It might follow that though our present community owes them some concern, it does not owe them concern equal to the concern it must show for pregnant women; someone who takes that view will accordingly take a more permissive attitude to abortion than someone who does not.) Future generations raise a parallel problem. Our collective policies of saving and conservation, broadly understood, require some assumption about the concern to which future generations are now entitled. Once again it is plausible to insist that those these will be persons they need not be counted as citizens the present community must treat with equal concern.

The demented stand in a different position from foreigners, fetuses and future generations, however, in the way I indicated. For the demented were moral citizens before they fell ill, so their case demands that we consider the conditions under which moral citizenship once acquired can be lost. It can, of course, be lost through voluntary act, someone ceases to be a moral citizen when he abandons his political citizenship for that of another nation; his former community need no longer treat him with equal concern. It is a very popular idea that moral citizenship can be forfeited as well as abandoned: that the government need not treat convicts with equal concern, for example, and that this justifies keeping them in jail, or even killing them, for the general good. But treating the demented as no longer moral citizens is justified only if moral citizenship can be lost involuntarily, through no fault of the former citizen. Allowing that would destroy the principal value of citizenship: it would make the obligation of the community, to treat all its members with equal concern, largely illusory, because the concern could be withheld when most needed. Citizenship defines the category of those whose misfortunes command the community's full attention; that principle would be fatally undermined, and left with no coherent force, if the most serious misfortunes released the community from its obligation to show any concern at all. Moral citizenship, once acquired, cannot be lost so long as the community's concern is appropriate. It embraces at least all sensate citizens, who can suffer pain or anxiety, and embraces them equally without regard for the degree of their rationality or general competence. The demented are not second-class moral citizens.

We have therefore answered our initial, threshold question from a variety of moral perspectives: even advanced dementia patients are within the domain of rights. We must now consider the more complex and detailed problem of the character of their rights, that is, of which rights they in fact have. In the next three sections of the essay we consider the three important and related rights I described earlier: rights to autonomy, beneficence and dignity. Then we consider the rather different and even more complex question of the rights demented people have to resources, and we shall finally inspect, as part of that discussion, the crucial assumption I have been making: that it makes philosophical sense to treat a demented person as the same person as the competent person who formerly occupied his body. It is worth noticing (as one more indication of its centrality) how that assumption figured in the argument of this section, the argument that the demented are within the domain of rights. I relied on it particularly in the egalitarian argument just completed. I said that the demented are moral citizens because moral citizenship, once acquired, cannot be lost voluntarily, and that assumes that the moral standing of a competent person remains attached to the demented person he becomes. If my assumption that personal identity survives dementia is unsound, the arguments of this section would not establish that the demented are within the domain of rights. Perhaps no arguments could.

III. Rights to Autonomy.

A. Contemporary Autonomy

It is a familiar idea in political philosophy that adult citizens of normal competence have a right to autonomy, that is, a right to make decisions about the character of their lives for themselves. Except in very special circumstances, we reject paternalism — forcing people to act in what the government deems to be their best interest — because paternalism denies that right to autonomy. So competent adults are free to make poor investments, provided others do not deceive or withhold information from them, and smokers are allowed to smoke in private, though cigarette advertising must warn them of the dangers of doing so. Autonomy is often at stake in medical contexts. A Jehovah's Witness, for example, may refuse blood transfusions necessary to save his life because he believes transfusions offensive on grounds of religious conviction. Or a patient whose life can be saved only if his legs are amputated, but who prefers to die soon than to live longer in what he would regard as intolerable circumstances, is allowed to refuse the operation. American law quite generally recognizes the patient's right to autonomy in circumstances like those.

How far do the demented have a right to autonomy? How far, that is, to they have a right to make decisions for themselves that others would deem not in their best interests?[13] Should they be allowed to spend or give away their money as they wish, or to choose their doctors, or to refuse prescribed medical treatment, or to decide which of their relatives will be appointed as their guardian? How far does this depend on the importance of the decision, and the degree of their incompetence? There may, of course, be some other reason, beyond autonomy, for allowing them to do as they please. They may become so agitated, for example, if prevented from doing as they wish, that though the decision they make is not itself in their interests, we do them more harm than good by opposing them. Our present question is whether we have reason to respect their decision even when this is not so, even when we think it would be in their best interests, even all things considered, to take some decision out of their hands.

We cannot answer that question without reflecting on the _point_ or _value_ of autonomy, that is, on why we should _ever_ respect the decisions people make when we believe these are not in their interests. One popular answer might be called the _evidentiary_ view: it holds that we should respect the decisions people make for themselves, even when we think these decisions imprudent, because as a general matter each person knows his own interests better than anyone else does. We may be right, on some particular occasion, in thinking that we know someone's best interests better than he does, but experience teaches us, according to this argument, that in most cases we will be wrong. So we do better for peoples' well-being by recognizing a general right to autonomy, which we always respect, than by reserving the right to interfere with their lives whenever we think they have made a mistake. If we accept this evidentiary account of autonomy, we will not extend the right of autonomy to decisions made by the seriously demented. For it is very implausible to assume that someone who is demented, who has lost the power to appreciate and engage in reasoning and argument, even generally knows what is in his own best interests as well as trained specialists, like doctors, do. In some cases that assumption would be incoherent: when, for example, as is often the case, the wishes and decisions of a demented person change radically from one bout of lucidity to another.

But the evidentiary view of the point of autonomy is very far from compelling. For autonomy requires us not only to allow someone to act in what he takes to be his best interests but to allow him to act in a way he accepts is not in his interests at all.[14] This is sometimes a matter of what philosophers call "weakness of the will". Many people who smoke would prefer not to; they do not think that smoking, all things considered, is in their best interests, but they smoke anyway. If we believe, as we do, that autonomy requires allowing them to act in this way, we cannot accept that the point of autonomy is to protect an agent's welfare. Sometimes people act against what they believe to be their own best interests for more creditable, even admirable, reasons. A Jehovah's Witness who refuses a blood transfusion acts out of convictions most other people think mistaken and irrational; but he acts out of conviction nevertheless not a mistaken view of self-interest. If autonomy requires us to respect such decisions, then once again autonomy is poorly explained on the view that the right to autonomy promotes the welfare of people making apparently imprudent decisions.

This suggests that the point of autonomy must be, at least to some large degree, independent of the claim that people know their own best interests better than other people can, and in that case it would not follow, just from the fact that a demented person will often be mistaken about his own best interests, that others are entitled to override the choices he makes. So perhaps the demented have a right to autonomy after all. The most plausible alternate view of the point of autonomy emphasizes, however, not the welfare of the choosing agent, but his integrity. The value of autonomy, on this view, lies in the scheme of responsibility it creates: autonomy makes each of us responsible for shaping his own life according to some coherent and distinctive sense of character, conviction and interest. It allows us to lead our own lives rather than being led along them, so that each of us can be, to the extent a scheme of rights can make this possible, what he has made himself. This view of autonomy focuses not on individual decisions one by one, but the place of each decision in a more general program or picture of life the agent is creating and constructing, a conception of character and achievement that must be allowed its own distinctive integrity. We allow someone to choose death over radical amputation, or even blood transfusion, if that is his informed wish, because we acknowledge his right to a life structured by his own values even when these are not ours.

If we accept the integrity view of autonomy, our judgment about whether some patient has a right to autonomy will turn on the degree of that patient's capacity for integrity. When a mildly demented person's choices are reasonably stable, and reasonably continuous with the general character of his life before he became demented, he can be seen as still in charge of his life, and he has a right to autonomy for that reason. But if his choices and demands, no matter how firmly expressed one by one, contradict one another, or reflect no coherent character, or perhaps even if they are radically discontinuous with his previous life, then there is no longer any integrity for autonomy to honor. He will not then have a right that his choice of a guardian, or about the use of his property, or about his medical treatment, be respected for reasons of autonomy. He has the right to beneficence to be discussed below, that is, that decisions on these matters be made in his best interests; but he has no right, as competent people to, himself to decide contrary to those interests.

I should emphasize that the decision whether a particular patient is sufficiently competent to have autonomy must be a general, overall judgment about his capacity for integrity, not a specific, task-sensitive judgment. The literature of dementia points out, perfectly properly, that competence, in the sense of capacity to grasp the factors on which some decision must be made, is relative to task: a patient who is not competent to administer his complex business affairs may nevertheless be sufficiently competent to decide whether to remain at home or to enter an institution, for example. Competence, in that task-sensitive sense, means the ability to grasp and manipulate information bearing on a particular problem, and this always varies, sometimes very greatly, among ordinary, non-demented people. I am more competent than you at some tasks, perhaps, but probably much less competent at others. Competence in the overall sense presupposed by the right to autonomy is a very different matter. It means, not the capacity to solve particular problems, but the more diffuse and general capacity for integrity: the capacity to see and evaluate particular decisions in the structured context of an overall life organized around a coherent conception of character and conviction. There will of course be hard cases, in which we will be unable to say, at least with any confidence, whether a particular dementia patient is competent in that overall sense. But the question of autonomy requires that overall judgment, not some combination of judgments about specific task-capability.[15]

B. Precedent Autonomy

So neither the evidentiary view of autonomy, nor the more plausible integrity view, recommends any right to autonomy for the seriously demented. But we have so far been considering the contemporary autonomy of a demented person; we must now consider the precedent autonomy of the person he was before. Suppose a patient is now incompetent in the general, overall sense just discussed, but that, years ago, when perfectly competent, he executed a "living will" providing that he was not to be kept alive by expensive medical treatment if he became permanently demented, or that his property was to be given to charity rather than used for his care. Does autonomy now require that such provisions be respected, by those in charge of the patient, if they think them against the patient's best interests? If we accept the evidentiary view of autonomy, we will think the case for respecting such precedent choices very weak. People are not the best judges of what their own best interests would be under circumstances they have never encountered, and in which their preferences and desires will undoubtedly have changed. If we accept the integrity view, on the other hand, we will be drawn to the view that precedent autonomy must be respected, because it seems essential to someone's control of his whole life that he be able to dictate what will happen to him when he becomes incompetent. A competent person, making a living will providing for his treatment if he becomes demented, is making the kind of judgment that autonomy, on the integrity view, respects, a judgment about the overall shape or character of the kind of life he wants to have led.

But it might now be objected that the right to autonomy is necessarily contemporary: that it is only a right that someone's present decision be respected. Certainly that is the normal force of recognizing autonomy. Suppose that a Jehovah's Witness, whose religious convictions so require, has signed a formal document stipulating that he is not to receive blood transfusions even if he, out of weakness of will, requests them when he will otherwise die. He wants, like Ulysses, to be tied to the mast of his faith. But when the moment comes, and he needs a transfusion, he pleads for it. We would not think ourselves required, out of respect for his autonomy, to disregard that plea to honor his former, formal request. We can interpret that example in two different ways, however, and the difference becomes important when we consider whether autonomy requires enforcing prior decisions about one's treatment when demented. We can say, first, that the later plea countermanded the original decision because the plea expressed a contemporary desire. On that view, it is right to defer to past decisions only when we have reason to think that the agent still wishes what he chose then: we treat the past decision, that is, as evidence of present wish, and disregard that decision when we have reason to think it is not in fact good evidence of that. So precedent autonomy as an illusion: we attend to past decisions only as rebuttable evidence of contemporary preference or choice. Second, we can say that the later plea countermands the original decision because the later plea counts as a fresh exercise of autonomy, that if we disregarded it we would be treating the person who pleads as no longer in charge of his own life. The difference between these two accounts of the force of autonomy is crucial when the conditions of autonomy no longer hold when someone changes his mind. Suppose that the same accident that made a transfusion medically necessary for the Witness also deranged him and, while still plainly deranged, he demands the transfusion. On the first view, we would not violate his autonomy by administering it; but on the second we would.

Which view of autonomy is right? Suppose we were confident that the Witness, if he receives the transfusion and lives, will become competent again, and will then be appalled at having had a treatment he believes was much worse for him than dying. In those circumstances, I believe, we would be violating his autonomy by nevertheless giving him the transfusion while he is deranged. That argues for the second view of autonomy, the view that endorses precedent autonomy. The deranged Witness does not object to the transfusion: he wants it. This is not, that is, like the case in which someone who objects to a treatment is asleep or unconscious when he needs it; in that case we can say (using a dispositional sense of objecting) that he continues to object then. If we withhold the transfusion from the deranged Witness, we withhold it in spite of the fact that he wants it then. We are relying on the fact that he does not have the capacity necessary for his wants to count in countermanding what he wanted when he was competent, and that means we are relying on the second view of autonomy's point. Someone might object that we are actually relying, not on any lack of capacity, but on the assumed fact that the Witness will regret the transfusion, if he receives it, when he becomes competent again. But we would take a different view if the Witness had not become temporarily deranged: suppose he pleads for the transfusion at the moment when he needs it, not because he is temporarily deranged, but just because he finds he wants to live at that moment, though we are confident that he will change his mind and be appalled at his decision tomorrow. If we would accede to his request for the transfusion when he wants it (as I believe we should), that shows that we are not relying, in the case when he has become deranged, just on the fact that we predict he will have a different opinion when he recovers his senses. That fact seems important, in that case, only because it confirms that he had not changed his mind when he was still competent to do so.

Our argument, then, supports the idea of precedent autonomy. A competent person's right to autonomy requires that his past decisions, about how he is to be treated if he becomes demented, be respected even if they do not represent, and even if they contradict, the desires he has then, provided he did not change his mind while he was still in charge of his own life. If we refused to accept precedent autonomy, and instead insisted that past decisions made when competent will not be enforced unless they represent the present wishes of the incompetent patient, we would be violating the point of autonomy on the integrity view. For competent people, concerned to give their lives the structure integrity demands, will naturally be concerned about how they are treated when demented: someone anxious to insure that his life is not then prolonged by medical treatment is anxious exactly because he thinks the character of his whole life would be compromised if that life were prolonged in that way. This argument has austere consequences, however. Many would be outraged by the prospect of denying an incompetent patient life-prolonging care he pleads for, of allowing someone to die who very much wants to live, just because, years earlier, he signed a document requiring this. I have been arguing that his right to autonomy — the right of the person he has become and remains — unambiguously requires that his pleas now be denied; he is not like the imagined

Jehovah's Witness who changed his mind when he knew he was dying.[16] We may be unable to deny him. We may think that people who refuse pleas for life for any reason are inhumane. Or we may have other good reasons for treating him as he now demands. But if so these are reasons that violate, rather enforce, his autonomy.

I end this discussion of autonomy with one final distinction. We must distinguish the precedent autonomy we have now recognized from other ideas with which it may easily be confused. Commentators and judges have said, for example, that crucial decisions affecting the care of dementia patients should reflect the decisions the patient probably would have made himself if he were competent. (So a patient's family succeeded in persuading a judge to terminate his care by arguing that he was a vital person who would not have wanted to languish in inactivity).[17] We must understand these statements as appeals to precedent autonomy. So we must require, before allowing these supposed past wishes any effect, evidence of an actual past decision or belief that contemplated at least the general circumstances the patient is now in. It is not enough to argue that a particular conviction (for instance the desire not to have one's life prolonged) would be more consistent with the patient's former habits and patterns of life than any contrary conviction. The point of autonomy, on the integrity view, is to allow an agent to construct his own life and character according to his own lights, not to allow others to make, for him, a life they think most consistent in ideal or character.

IV. Rights to Beneficence

A. A Fiduciary Right

When one person is entrusted to the charge or care of another, the former has what we might call a right to beneficence: a right that the latter make decisions in the former's best interests. This fiduciary right is a familiar idea in both law and morals: a trustee must act in the interests of the trust's beneficiaries, the directors of a corporation must act in the interests of its shareholders, doctors and other professionals must act in the interests of their patients or clients. The right to beneficence is not a right that any particular person assume that duty of care; no one has a right that anyone else take up a fiduciary's duties towards him. The right takes hold only when someone does take up that role. Nor is it a right that any particular resources be put at the disposal of the fiduciary; that right, for the demented, will be considered later. The right of beneficence is only a right governing the use of whatever resources are made available for the beneficiary's care.

Since a beneficiary may take a different view of his own interests from the view a fiduciary takes, the right of beneficence is different from the right to autonomy we just discussed, and may in some circumstances conflict with it. We noticed one potential conflict a moment ago, between the best interests of a demented patient and the precedent autonomy of that patient before he became demented. We should postpone considering such conflicts, however, until we have a better grasp of the content of a seriously demented person's right to beneficence. We have no reason to doubt that he has such a right: it would be wrong for his doctors and others charged with his care to ignore his interests in what they do. But we face an obvious problem in considering the consequences of that right. What *are* the best interests of someone seriously and permanently demented? We must begin by noticing an important distinction between two crucially different kinds of interests people have. The distinction is important in philosophical psychology generally, and throughout moral and political philosophy. But it is indispensable in disentangling the various issues raised by our present question, about the nature of a demented person's right to beneficence.

B. Experiential and Evaluative Interests

Most people in normal mental health worry or are concerned about two general kinds of interests they believe they have. First, they care about the felt quality of their future experiences. They dread future pain or discomfort, anticipate a good film or meal, and relish the prospect of travel, or of other forms of pleasure or enjoyment. I shall call these their *experiential* interests. Second, they care about the overall value or worth of the life that they are leading. They want it to be a *good* life, a life full of the associations, experiences and achievements a good life should have, unmarked by the blemishes that make a life bad: the kind of life in which they can take pride or some other form of satisfaction. These concerns describe their *evaluative* interests. Most people think about their evaluative interests much less frequently than about their experiential interests; the former come into play, self-consciously, only on those occasions when people are aware that a particular decision will affect the character of their life as a whole for better or worse. Many people never attend deliberately to their evaluative interests at all (though some of these, who want a spontaneous life because they think a planned or often re-examined life unattractive, are pursuing what they take to be their evaluative interests precisely by not attending to them).

The distinction between these two kinds of interests is very important and complex, and I shall explore it, in this essay, in only a cursory way, not even noticing several of the philosophical issues an extended treatment of the distinction would encounter. I shall try to show only that it is a distinction crucial to understanding the situation and rights of the demented, and most of these philosophical issues can be neglected for that purpose. Some philosophers would reject the distinction as superficial. Some utilitarians, for example, think that all interests are at bottom experiential. We take an interest in having a life good as a whole, on their account, only because we predict that we will be unhappy when we grow dissatisfied with the life we have already led. That seems to me to put the matter the wrong way around: I do not care about the shape of my life as a whole because I predict I will be unhappy if I think my life a poor one, but rather I am unhappy, in that event, because I think it so important that it be good. Other philosophers collapse the two kinds of interests in the other direction: they think we dread pain to come, for example, only because we think a life with pain a worse life to have led. That also seems wrong: we worry about painful or disagreeable moments in our future not because we think these mar the overall success of our life, but, at least often, in spite of the fact that we do not, and when the pain or discomfort is past we may count it as no blemish at all, or even as a kind of achievement. No doubt the two kinds of concerns do overlap to a considerable extent for many people: they think their life will have been a worse life, in the evaluative sense, if it includes or avoids what they hope for or hope to avoid experientially. But the quantitative accounting is nevertheless usually very different even in such cases. Even when an old person fears future pain intensely, or despairs because he has learned he will die soon, he is unlikely, except in very special circumstances, to think that his life as a whole is made a dramatically worse life by that pain, or would have been dramatically better if he had lived some years longer. We understand the complexity of human emotion better by contrasting rather than assimilating the two ways in which people attend to their own interests.

One of the differences is specially important for this essay: time plays a different role in each kind of concern. Experiential interests are forward-looking and therefore radically time-sensitive. I care, in the experiential way, about pain to come, but not about pain I have already suffered. I want, in that way, not to die soon, because this will cheat me of experiences to come, but I do not want already to have lived longer, that is, to have been born earlier than I was. Evaluative interests, in contrast, are not temporally indexed in that way. If I want my life to include certain kinds of achievement, only because these will make that life a better one, I will be indifferent as to whether the achievement is in the past or to come. If I would prefer my life to be longer than in fact it will be, not because I anticipate pleasure or enjoyment in future experiences, but because I count living longer in itself an achievement, as many people do, then I would be indifferent as to whether the longer life would have been secured by my having been born earlier than I was or dying later than I will.

A second difference is also important for us: though a person can judge his own interests differently at different stages of his life, the character of the conflict between these judgments is different with respect to the two kinds of interests. People's opinion about both kinds of interests often change over time. Someone may work to bring about particular kinds of experiences later — he may plan and budget for a trip — that he finds he does not enjoy, or enjoy as much, as he predicted. Or he may take important decisions — become a lawyer and join the bar — because he presently approves of a kind of life he later, when it is to late, thinks not a valuable life for him to have led after all. In both cases, as we might put it, his later self "disagrees with" the judgments his earlier self made. But the character of this disagreement is different. A disagreement about experiential interests proves that the original judgment, which was in the character of a prediction, was in fact wrong as things turned out. The earlier self made a mistake about what the later self would in fact enjoy: the former thought the latter would delight in a safari, but he did not. In the case of evaluative interests, it does not follow from the disagreement that the earlier self made any kind of mistake. The judgment someone makes deciding to go to law school, that the life of a lawyer is a valuable one for him, is not a prediction in the way that the judgment that he will enjoy a safari is. If he changes his mind later external observers will not be entitled to say, for that reason alone, that his original opinion had been proved wrong. They may think that he was right the first time, that his later, changed opinion was a change for the worse.

A fiduciary — someone who acts in the best interests of another — must attend to this distinction. He acts in that person's experiential interests if his decision in fact improves the experiential quality of that person's life, if, that is, that person then enjoys his life more. But it does not follow that the fiduciary acts in that person's evaluative interest just because his decision has that consequence.[18] We need further distinctions to describe a range of possibilities here. A doctor, for example, acts in his patient's subjective evaluative interest when he changes the patient's life in a way the patient regards as an improvement.[19] He acts in what he takes to be the patient's objective evaluative interest when he changes the patient's life in a way that he, the doctor, believes makes it better. Of course, any reader who is skeptical that lives can be "objectively" better or worse will think that no one ever does or could act in another person's objective evaluative interest when he acts against his subjective evaluative interests. In any case, acting against someone's subjective evaluative interests is normally an insult to that person — a particularly objectionable form of paternalism — that at least usually cannot be justified.[20].

C. What Interests do the Demented Have?

Even a seriously demented person (unlike a permanently comatose person) has experiential interests. He remains capable of enjoying comfort and reassurance, and he has fears about his future and perhaps, to some diminished degree, even pleasurable anticipation. But by the time his dementia has become serious he has lost the capacity to attend to or even appreciate his evaluative interests, because these can have no meaning for him. He is ignorant of self not just in the way an amnesiac is, not just because he cannot identify his past, but more fundamentally because he has no sense of a whole life — a past joined to a future — that could be the object of any evaluation or concern as a whole. He cannot have the kinds of projects or plans, or survey and compare sets of these, in the way evaluative concern demands. Our normal use of the idea of best interests, in other words, presupposes that the person whose interests we are judging has a coherent, stable, complex and structured system of values. Even when we are tempted to set aside his particular choices, on the paternalistic assumption that we know what is in his interests better than he does, we appeal to his underlying structure of values, which we feel his present choice disserves out of ignorance or weakness of the will, to justify our choice for him.

He has then no contemporary subjective evaluative interests. But does he nevertheless have objective evaluative interests to which a fiduciary might attend? It is certainly not true that someone lacks objective evaluative interests whenever he lacks opinions about them. We often say, of someone who lives for the moment and cares only for experiential interests, that he is wasting his life, and that judgment assumes that he has evaluative interests even though he is wholly unaware of them. Does it make a difference that the demented person, unlike the person wasting his life, lacks even the capacity to attend to his evaluative interests? Babies and young children do not have that capacity either, and yet we assume that they have evaluative interests. A large part of early education is designed to enable them to lead valuable and not just enjoyable lives. Of course, there is an important difference, which we can express temporally, between a baby and someone permanently demented. A baby already has evaluative interests, it might be said, because what happens to him or her later in life can make that life more valuable than it would otherwise be. But nothing that happens to someone after he has become demented can improve the evaluative quality of his life overall, making it a more valuable life than if he had died instead of becoming demented.

There is an important truth in the comparison. If we think of a demented person's life in only a forward-looking way, as the life he will lead from now on, there seems very little point in speculating about his evaluative interests, about what would make that life, so defined, more or less valuable, because he will from now on be capable of none of the achievements or attachments that we normally think give value to a life. Value, we might say, cannot be pored into a life from the outside; it must be generated by the person whose life it is, and this is not possible for someone who will always be demented. But we are now assuming that a demented person is continuing the life of someone who was competent before. So when we consider how what happens to a demented person can affect the value of his life, we must consider his whole life and not just the sad final stages of it. The question whether a demented person has evaluative interests (and if so what these are) therefore asks whether and how events in the life of a demented person can affect the overall character or value of his whole life.

Most people think the value of their life can be affected by events after their death: they think their life would be a better one, for example, if projects they have began flourish after they are dead, or if they are remembered affectionately or well, and worse if their projects fail or they are forgotten or remembered badly. So events taking place after a person has lost control of his life can, or so most people think, affect its value, and if so evaluative interests survive death. It is at least equally as plausible that evaluative interests survive dementia, and most people who have considered the possibility of dementia plainly think they do. Many people who are now competent, for example — almost all those I have discussed the matter with — would prefer to die immediately than to live on even in comfort if they became demented. That preference makes sense only as a judgment reflecting evaluative rather than experiential interests. They think that their life would have been a worse life overall if it includes a substantial period in which they are demented.

What reasons might they have for that view? They fall into three types. The first tracks some of the reasons people have for caring, prudentially, about what happens after their death. People might think, for example, that their life is a worse life if they are remembered as demented, if their situation then dominates the image others are likely to have of them. The second is more attractive. People might think their life is made overall a worse life if they become a substantial burden to those they love, as demented people typically are. The third is specific to dementia: many people simply hate the idea of being demented, whether or not others think less or differently of their lives for that reason or whether or not they burden others. We cannot dismiss that sense as irrational. We noticed, in considering autonomy, that people think it crucial to the value of their lives that they be in charge of them: being in charge, we might say, is a fundamental, even constitutive, evaluative interest. Since people have a sense that their life continues even when they are demented, they can sensibly regard that part of their life, in which they are not at all in charge, as damaging its quality overall, because dementia is not, for them, a neutral state. They count it bad to be alive in that state.

D. Conflicts of Interest

We are considering not whether competent people think they have evaluative interests even after they become demented, but whether they do. I appeal to familiar beliefs of competent people only to indicate the popularity of the opinion that the demented have such interests, and to suggest the character of these interests if they do exist. We might decide, after reflection, that the claim that the demented have such interests is a mistake. We might well reach that conclusion, for example, if we decided, after our later consideration of the matter, that it is a mistake to think that personal identity survives dementia, that is, that a demented person is leading part of the same life as the competent person who occupied his body before. We might then think that since the opinion of competent people, that it matters to their lives how they are treated after they become demented, rests in large part on a mistaken belief about personal identity, it is therefore itself a mistake. Even if we decide that my assumption about personal identity is correct, we might still decide that the popular opinion that the demented have evaluative interests is wrong, or disagree with particular people's opinion about what these evaluative interests, considered objectively, really are. We might think, for example, that it does not affect the value of someone's life how he is remembered, or whether or not he is in charge of it during some period in which he lacked the capacity to take charge.

How should we approach the question, then, of how far and how a fiduciary should attend to the evaluative interests of a demented person? We can sharpen that question by supposing that the evaluative interests of a demented person, if he has any, might conflict with his experiential interests. We should therefore return to the difficult case we considered earlier. Suppose someone who is seriously and permanently demented is ill and will die without life-prolonging medical treatment, and that resources are available to provide that treatment. Suppose his experiential interests would be served by prolonging his life: he wants to live, and will have pleasurable experiences if he does. Should a fiduciary — a doctor, for example — consider whether he has competing, evaluative interests that recommend against prolonging his life? If so, what standards should he use to decide whether he has such interests, and how the conflict, if he does, should be resolved?

I argued, in the last section of this essay, that if the patient had addressed these issues himself, and made a decision about how he wanted to be treated in this event, his right to autonomy would normally require others, including fiduciaries, to respect that decision. In order to concentrate on the different right to beneficence, therefore, we should now assume that he has made no decision himself, that he never considered whether he would want his life extended if he were permanently demented. A fiduciary would then have to choose between the following two strategies. He might decide that in these circumstances the patient's evaluative interests should be ignored and only his experiential interests taken into account in deciding where his best interests lie. Or he might decide that the patient's evaluative interests do count, in which case someone — the fiduciary or someone else — would have to decide what those evaluative interests, properly understood, require, and how weighty, in contrast to the experiential interests, they are. (I shall ignore the question, here, of which person or group should in fact make this decision. The candidates include the fiduciary, relatives or the community itself through some political decision. If we decide that someone should try to determine and enforce the patient's evaluative interests, the question of who should do so would obviously be of very great practical importance, but it will be helpful to abstract from that question in considering whether anyone should).

Autonomy requires that competent people be left in charge of their own lives: that is, that they be permitted to decide what is in both their evaluative and experiential interests and, if conflicts arise, how to resolve them. It is paternalism for a fiduciary to act on his own judgments about the interests of another when these do not reflect what that other person believes himself, and the paternalism is most serious and objectionable when the fiduciary's judgments are judgments of evaluative rather than experiential interests. (My autonomy is insulted when government requires me to wear seat-belts in my own interests. But the insult is much greater when it censors my reading on the ground that some books might persuade me to a worse view of what a valuable life is.) These observations might be thought to require the first of the two strategies I just distinguished. We might say: "Since paternalism is wrong, a fiduciary should avoid it whenever possible, and particularly when it means foisting his own judgments about what makes life valuable on the patient. We are assuming that a demented patient can and does have opinions about his own experiential interests: he wants some things and experiences and to avoid others. So it is not necessary for the fiduciary to make any evaluative judgments for him, because the fiduciary can be guided by the patient's experiential interests alone. So if we accept that the fiduciary should act in whatever way will minimize paternalistic interference in the life of the patient, we would recommend that course, and so recommend, in the case we are considering, the life-prolonging treatment."

But this argument makes an assumption we must now expose. Why is evaluative paternalism wrong? What is its special vice? When we considered the point of autonomy, in the last section, we distinguished two views: that autonomy is desirable on evidentiary grounds, because people are more likely to know their own best interests than others are, and that it is desirable because people must be allowed to take responsibility for their own lives. We can distinguish two matching accounts of why evaluative paternalism is wrong: because others are likely to make someone's life a worse life when they intervene, and because intervening spoils the control people should have over their own lives. Neither of these reasons why we might think paternalism normally wrong holds in the case of dementia. Since someone demented is incapable of judging his evaluative interest, we cannot say that he is likely to know his own interests better than others can, and since he is not in control intervening cannot spoil his control. The argument of the last paragraph therefore takes some different view of the vice of evaluative paternalism: it holds that this is wrong _in itself_ and not just because of the consequences it might have for its object. Most people do not think evaluative paternalism wrong for young children: their education is normally designed with the end that their lives be better lives. It might be objected, to that comparison, that good education broadens the choice a child will later have; it does not dictate one choice irrevocably, as a fiduciary would do for his charge if he withheld life-prolonging treatment on the grounds that an early death made his life better. But in the circumstances we are considering, _either_ choice a fiduciary makes is irrevocable, and his decision to ignore what most competent people would think the main issue the choice involves — whether living in a demented state makes the whole life worse — seems perverse, a piece of methodological fiat that makes it more likely that, of the two irrevocable choices that might be made, the wrong one will be selected.

So the argument for ignoring evaluative interests drawn from paternalism turns out to be very weak. We must now consider a different argument: that in the circumstances of dementia evaluative interests become less important and experiential interests relatively more important, so that fiduciaries have that reason for ignoring the former and concentrating on the latter. But both wings of that suggestion are flawed. It is of course true — it is part of what we are assuming in setting our problem — that a demented person has no sense of his own evaluative interests. He is no longer capable of appreciating the character of his life as a whole, or why that life might be a better one, all things considered, if it ends soon. But he was concerned, when he was competent, that his life be a good one, and his concern, then, included a concern about how he would be treated during his whole life and not just that part of it during which the concern was lively. If we suppose that the interest ends when the concern does then we have made one of the mistakes we noticed earlier. Either we have collapsed evaluative into experiential interests, or we have divided the person whose interests the fiduciary is charged with promoting into two people, a competent predecessor who had evaluative interests but who has now disappeared and a demented successor who has no evaluative interests at all. In either case we have begun to think of people not as they think of themselves.

Nor do we have any reason to count experiential interests as more important when someone is demented than when he is competent. On the contrary, they seem less important then, even as experiential interests. We noticed, in considering the difference between experiential and evaluative interests, the overlap between them and the way in which satisfaction of one set contributes to satisfying the other. We take more pleasure in experiences that develop and use capacities we think we ought to have, for example, and we count our life better, in the evaluative sense, for being rich experientially, that is, for being full of experiences in which we can take delight. In dementia, however, even pleasant experiences make no evaluative contribution, because they cannot be perceived as exploiting desirable capacities. Many people recognize this in the popular judgment I reported: that it would be better for them to die than to live even a comfortable life with sharply diminished mental capacity. They are not merely recording, in that opinion, the triumph of evaluative over experiential interests, but also their sense that any pleasure they cannot savor, by connecting it to some larger and satisfying view of character and achievement, is thin and trivial.

Fiduciaries, then, have no justification for simply ignoring a demented person's evaluative interests. They have a responsibility to act in his interests overall and they (or some other person or group) must decide, for example, whether it is against his evaluative interests to receive life-prolonging treatment, and, if so, how the conflict between evaluative and experiential interests should then be resolved. The view that prolonging his life would be against his evaluative interests is, as I said, a popular view. The argument for it is straightforward and powerful. Some kinds of experiences and achievements make a life that contains them a better life to have led; some make it a worse one. The seriously demented stage of a life can contain almost nothing that could plausibly be thought to make that life better in the evaluative sense. Experiences in such a life cannot be considered rewarding, because that requires a sense of personality and agency that serious dementia excludes, nor as achievements, because that requires continuity of project and fulfillment. Though I remarked, earlier, that some people think a life better just because it is longer, no matter what the value of the additional life considered on its own, that view seems to demean rather than celebrate life, and most people would reject it. The demented stage of a life can certainly, however, contain experiences that make the life of which it is a part worse. Severe pain or anxiety makes a life worse, and so do the various forms of indignity, to which demented people are especially subject, that we consider in the next section. And we have already noticed other ways in which dementia may make a life worse: dependence, burden and image.

A fiduciary (or someone else or some other group charged with the decision) may plausibly decide, therefore, that it is against the evaluative interests of a permanently demented patient to prolong his life. Since that is my own view, I will assume, in the argument that follows, that we decide it is the correct one. (I make that assumption only to illustrate the importance and consequences of any such decision, and my argument does not, therefore, depend on accepting this particular, or any other, view of what the evaluative interests of a demented person actually are.) What should be done, then, if the patient wants to live, and will not suffer great any pain or anxiety that makes this against his distinct experiential interests? I claim that a great many people, when competent, would want not to have their lives prolonged if they became demented. But I do not claim that all would, and we cannot resolve the apparent conflict by appealing to any supposed consensus. I would myself stand on a different principle: that evaluative interests are both more distinctly human, and more important and fundamental, than experiential ones, and that we honor people by undertaking to look after these fundamental interests when they cannot do that for themselves. The more fundamental standing of evaluative interests flows from their character. It would go too far, I think, to say that people care about their experiential interests only because they care about evaluative ones. Experiential interests seem more biological than reflective in origin. Many people rarely reflect, with any degree of attention, on evaluative interests, and those who do often nevertheless choose a life they regard, in the abstract, as less valuable because it is easier or more pleasant. But evaluative concern nevertheless has a special standing that can be captured in the language of second-order wishes or preferences: anyone who thinks he would have a better life if he did not care so much for his experiential interests is likely to wish he did not. Or that his character would be better — he would think more of himself — if that were so. The principle I recommend — that a fiduciary should take over a person's responsibility to make his life as good a life as it can be when that person is no longer capable of this himself — can therefore be said to take the view of people we are assuming most people would like to take of themselves.

If so, then it follows that the right to beneficence includes the right not to be given life-prolonging treatment when seriously and permanently demented. Of course it includes much else as well — it includes the right to have pain and anxiety alleviated, for example. I have emphasized the life against death issue because that is the most dramatic of the decisions a fiduciary might have to make, or that others may have to make for him. And of course my claim that it is in a demented person's interests not to have his life made longer is controversial. Some people might disagree; they might think that it is always in any person's interests to live longer, at least when this can be done without pain. I have tried, not to support my own convictions, but to explore the complexity of the issue of what is in the best interests of a demented person, to show the strands of decision that must be distinguished and then woven into an overall judgment of what the right to beneficence requires.

We should look back, before leaving that right, to consider how it might conflict with the right to precedent autonomy we discussed in the last section. I imagined this situation: someone when competent provides, in a "living will", that he is not to be kept alive by expensive care if he becomes demented. But when he is demented he insists on and pleads for that care. We now see that this story need not, after all, present any conflict between autonomy and beneficence. If I am right that it is not in the demented person's best interests to be kept alive, we have no reason of beneficence for providing him the treatment he now demands. We may have other reasons for providing it — we may not want to live in a society that denies pleas for life from anyone — but we may now say that these are reasons of neither autonomy nor beneficence: giving him what he asks cannot be acting for him in either of these ways.

But now imagine a different, almost reversed, story: suppose that someone, when competent, asks that every means be used to keep him alive as long as possible if he becomes demented. (Or that we have good reason to think he would have made that request if he had thought it necessary). Now, if my assumption about his best interests is sound, the story does present a conflict between precedent autonomy and beneficence: what he asked before is against his interests now. How should that conflict be resolved? The right to autonomy is not a right to any particular resource. But suppose that the patient, when competent, provided the resources necessary to prolong his own life, or that his relatives are now prepared to provide these. It would be an act of deep paternalism for fiduciaries to refuse to spend these funds that way. Once again, there might be other reasons for their refusing to honor his past request, or for the community not allowing them to do so. But it would be unjustified paternalism to ignoring them appealing to the patient's contemporary best interests alone.

V. The Right to Dignity.

The idea of a right to dignity is used, in moral and political philosophy, in a variety of ways and senses. Sometimes, for example, it is understood as the powerful if vague right to the conditions, whatever these are, in which genuine self-respect is possible or appropriate. In this section, I shall be considering a different, more limited, idea: that people have a right not to suffer *indignity,* which means not to be treated in ways that, in the particular culture or community to which they belong, are understood as showing disrespect. Every civilized society has standards and conventions defining these indignities, and these differ, to some degree, from place to place and time to time. We often appeal to these standards in defining the minimum conditions of decent custodial care; we say, for example, that prisoners who have been convicted of even serious crimes are entitled to dignity in their punishment, and think this requires that jails be clean, that prisoners not be abused, and that they be allowed at least a certain level and kind of privacy.

A parallel claim is made on behalf of the demented in the care of the community. It is said that they, too, have a right to dignity, in virtue of which they must be kept clean when they cannot or will not clean themselves, must not be herded together in crowded conditions that allow them no genuine privacy, and must be shown some level of individual attention and concern by, for example, not just ignoring their complaints or sedating them to make them more tractable. This supposed right to dignity is in many ways treated as more fundamental than the right to beneficence we considered in the last section. That latter right, as I emphasized, is only a right that whatever resources are available for someone's care be used in his interests; the right to dignity is more imperative because it is understood to require the community to deploy whatever resources are in fact necessary to secure the dignity it commands. (The two rights are even more plainly contrasted in the case of prisoners. We do not require that jail conditions must be arranged in the best interests of the inmates, but we do insist that these conditions respect their dignity.)

Do the demented really have that right to dignity? Do they have it even when they are not competent to appreciate or suffer from indignity, or in any case seem not to care about it themselves? Or is our concern for their dignity then only a matter of sentimentality we cannot and should not afford? These are questions of considerable practical importance. It is expensive and tedious to keep seriously demented patients clean, expensive and difficult to provide enough space to assure each of them some privacy when he or she wants it, expensive and exasperating to give each of them the personal attention they often crave. Once again, we can answer the difficult question whether the demented have a right to such treatment, in the name of their right against indignity, only by reflecting further on the point of that right when we acknowledge it for the fully competent. Why do we care about indignity? Why do we care so much?

One theory treats indignity as wrong because very much contrary to our experiential interests. This theory supposes that indignity causes its victims distinctive and specially severe mental pain, that people resent and therefore suffer more from indignity than from other forms of deprivation. If their indignity is sufficiently serious and protracted, moreover, they will lose the self-respect dignity protects, and then suffer an even more serious form of distress: self-contempt or self-loathing. If this experiential account of dignity is sound, then the seriously demented (or at least many of them) may have no right to dignity after all. Seriously demented people may or may not want to be clean, or to have their privacy respected, but few of them have the necessary sense of self-identity to suffer a distinctive distress, different from the distress they suffer when any other request is refused, through what they can recognize as an insult to their self-esteem. Self-respect, like autonomy, requires a considerable degree of general competence; it requires, in particular, a sense of self-identity over time which seriously demented people have lost. (Self-hatred or loathing requires an even sharper sense of identity, and though some people feel that intense distress when they realize they are becoming demented, it has disappeared when the dementia becomes complete.) So on the experiential account of dignity it seems dubious that the demented have any general right to dignity. Concern for their self-respect does seem, on that view, only an expensive piece of sentimentality, like providing hairdressers for the comatose. Of course, even if we take that view of dignity, we may still think it important to maintain the demented in circumstances of dignity out of respect for the sensibilities of their relatives or others who will otherwise suffer outrage and guilt. But if it is true that the patient himself suffers no distinctive distress of indignity, his relatives might be led to see that their own indignation and guilt is misplaced. In any case respect for their feelings does not require us to recognize any general right of dignity for the demented, a right a demented patient would have even if he had no relatives or friends who would care.

The experiential theory of indignity, however, is unpersuasive, because it cannot explain central features of the use we make of the idea of indignity. Most of us think that slaves live in the ultimate indignity even if — particularly if — their subjugation is so complete that they believe their slavery appropriate and take no offense in it. The experiential theory also neglects the fact that, for us, dignity has an active as well as a passive voice, and that the two are connected. We disapprove of someone, and say he has compromised his own dignity, when he is so indifferent to hygiene that he lives in filth, or when he neglects or sacrifices the independence we think dignity requires, or debases himself, in ways we call undignified, for some immediate advantage. And we think that someone who acts in an undignified manner acts worse, and has more to be ashamed of, when he does not recognize the indignity he has brought upon himself. If the experiential account of indignity were right, these critical attitudes would be perverse; on that view someone who does not mind what for others would be an indignity might be unusual, but he would not be debased, and an unrecognized indignity would be no indignity at all. Nor can the experiential theory explain why the greatest indignity we can inflict on someone is to make him unconscious of other indignities, for example by sedation or brainwashing.

We can account for our full concern about indignity, therefore, only by rejecting the experiential theory of that concept in favor of a more evaluative theory. Indignity is a special sort of harm, whether self-inflicted or inflicted by others, not because it causes mental suffering, but because in some way it makes the life of its victim a worse life to have lived. Indignity is not bad, on this evaluative account, because it produces suffering, but rather produces suffering, when it does, because it is recognized as bad, and this explains why the harm of indignity is not less, but if anything greater, when the agent does not recognize that his dignity has been compromised. Is an evaluative account plausible? Is it plausible that living in circumstances of indignity makes a life a worse life? The fact that the content of indignity is at least partly culturally fixed might seem an argument that this is not plausible. How can living in filth make a person's life worse if he does not mind it? How can this depend on whether others in the society happen to believe that it does?

But that objection ignores what we might call the social meaning of indignity. The conventions of dignity furnish a vocabulary for gestures of respect and disrespect, including self-respect and its denial. When we insist that prisoners, for example, must be treated with dignity we mean that it must be recognized, in the way our culture provides for the purpose, that they remain members of the moral community, creatures whose fate is still of special concern to the rest of the community because they are still people. It is very far from absurd that someone's life is more successful when that moral standing has been recognized within his community, and worse when it has been denied. We noticed, in considering the various forms of evaluative interests most people recognize, that many of these touch reputation and image: we care about other peoples' attitudes to us. We care in the evaluative way: we care about their attitudes even when we are ignorant of them and even after we are dead. In the context of that general concern, it is more than plausible to count the fundamental recognition indignity denies as peculiarly important, and so the view I am trying to defend, that indignity offends our evaluative interests, is neither mysterious nor disconnected from our other beliefs and convictions.

The crucial question, then, when we consider whether the demented have a right to dignity, is not the question I first identified, whether they are capable of sensing indignity the way competent people can, or whether they resent it the way competent people do. It is the different question we have already answered: whether the demented remain members of the moral community who are entitled to be recognized under that title. We must remind ourselves that the interests we are studying, and the right we are considering, do not belong simply to a demented stage of a person, a stage that cannot acknowledge the interest or appreciate the right. We are recognizing, here as in past parts of the argument, the evaluative interests of a person who has become demented. We treat him with dignity, not out of sentimentality or misplaced guilt, but because we believe we would harm him, in a special but nevertheless serious way, if we disowned him now.

VI. Competence and Resource

A. The Costs.

In the remaining sections of the essay we consider the most complex and, from the standpoint of political morality, the most important of the philosophical issues raised by the increasing costs of senile dementia. The expenses of caring for seriously and permanently demented people fall into two main classes. First, the seriously demented require custodial care, and as the disease progresses this must be round-the-clock care. The expenses of custodial care can be monumental: the average nursing home charge in Manhattan, for example, is $_______ a year. Second, particularly because they are mainly old, the demented have substantial medical needs that are quite independent of their dementia: the medical expenses of even the fully competent elderly are disproportionately great. A demented patient may need expensive medical care in order to save or extend his life in the face of life-threatening diseases: he may need treatment for cancer or an organ transplant or coronary surgery.

The present public provision for the demented, in the United States, is complex but it is far from plain that it expresses any coherent welfare entitlement theory. Custodial care is not provided under the Medicare program, which is available to all the elderly. Custodial care may be provided under Medicaid, but Medicaid is available only to the very poor, and therefore not to most dementia patients until their own resources have been all but exhausted. The poverty threshold for Medicaid has led some victims and their families artificially to exhaust resources: patients becoming demented transfer their property to others, and they sometimes divorce so that their spouses' resources are not counted in deciding their eligibility. The custodial care Medicaid provides is, in any case, considerably less ample than the care provided for people who can afford more. On the other hand, dementia is not taken to be a reason for withholding life-prolonging medical care that would otherwise be available. Many states have adopted legislation providing for "living wills" that allow competent people to provide that they are not to be kept alive if they become demented,[21] and some courts have allowed the family of a demented patient to withhold life sustaining treatment on a showing that the patient's style of life was such as to suggest that he would not want to continue living in those circumstances.[22] But dementia is not in itself taken to be a reason for providing less intensive medical treatment than a patient would otherwise receive.

We need a more systematic and efficient scheme of public support. What form should it take? Is a victim of senile dementia entitled that the community as a whole, through some level of government, bear all or part of some or all of these two groups of expenses? If so, is every victim entitled to that public support? Or only those who cannot, or whose family cannot, afford it themselves? To what kind of treatment and care are victims entitled? To both custodial and medical care, or to one but not the other? If government should provide custodial care, how much such care — at what level of comfort, companionship and privacy

— should it provide? If it should provide medical care, should the fact that the patient is demented justify providing less medical care for treatment of his dementia-independent disease? If we believe that government should provide life-saving treatment (like renal dialysis) for everyone who cannot afford it for himself, for example, does it follow that government should provide such treatment for the seriously demented as well as the normally or partially competent? Are there limits to government's responsibility for medical care? What standards govern these? Are demented people entitled to every kind or type of treatment that might improve their welfare or life-expectancy? If not, to what lesser level of treatment? What sort of argument could the community use to justify some lesser level of care?

The discussion of earlier sections of this essay, about the rights demented people have to autonomy, beneficence and dignity, is pertinent to all these questions, and I shall draw upon it. But so is a domain of political morality we have not yet considered: distributive justice. Any view about the responsibility of government to provide medical or custodial care for those unable to provide it for themselves rests in the end on some more general thesis about the moral responsibilities of the community as a whole towards each of its members. The American people have been divided about that responsibility over their entire history, and the division is particularly sharp now. We must try to identify the general models or approaches or impulses reflected in the national debate about public responsibility for individuals, and in particular about the role government should play in meeting health care costs, noticing the philosophical antecedents of each, and its implications for the special problem of serious and permanent dementia.

B. Models of Welfare Entitlement

Some people would give a short answer to the list of questions I identified, about the welfare entitlements of the demented. They would say that since people are responsible, as individuals, for their own fates, the government has no welfare obligations to anyone, and that someone who becomes demented must be cared for out of his own resources or those of relatives and friends willing voluntarily to help.[23] The pure version of this austere view argues that the government should make no contribution to the care of dementia victims in any circumstances. But though the idea that individuals must take responsibility for their own fates is more popular in American politics now than it has been for some time before, it is not popular in that pure and relentless form. Even its most devoted partisans accept that government has some responsibility in extreme cases, when a fellow citizen is in wretched circumstances through no fault of his own, and his condition can be improved by relatively small public expense. So even they need some theory or standard justifying this exception to their general principle, or at least some general description of when it holds. Most people feel more generous impulses towards the handicapped including the demented. But even those who support large public programs of assistance are generally unclear about the basis for this assistance; in particular they are unclear how far the handicapped have a right to it. That question is crucial not only for fixing a floor under the overall contribution the community must make for the handicapped, but also for fixing how that contribution must be distributed among them.

We might distinguish four different approaches we might take to the question how far and why the community should make provision for the sick and handicapped. The sympathy approach (as I shall call it) argues that community provision is justified and required because it institutionalizes the sympathy or love or identification citizens of adequate means should feel for less fortunate fellow citizens. That is an attractive description of the general motives many citizens feel they have for sponsoring or supporting public provision. But is not sufficiently detailed or structured to provide a justification for any particular form or level of public support; it states a reason but not an approach. The problem of medical care illustrates that limitation dramatically. Technology has produced devices and procedures of undoubted value in improving life-expectancy, from cat-scans and non-invasive diagnostics to transplants of a variety of organs. A community that undertook to provide the most powerful technology available to every citizen, regardless of cost, would have no resources for other purposes. Sympathy and identification provide no standard for deciding how much and what level of care should be provided for all, short of that unattainable ideal.

The utilitarian cost-benefit approach offers such a standard: it insists that any public expenditure be designed and directed so as to maximize the general benefit of all such expenditure, measured by its total contribution to welfare, to the community as a whole in the long run.[24] The philosophical background of this cost-benefit approach is utilitarianism, the general theory that all government programs and policies, including policies of taxation and redistribution, should be governed by the sovereign imperative that all such programs should aim to improve the average level of happiness, prosperity and success in the community as a whole, trading off welfare losses to some against greater gains to others.[25] Under the cost-benefit approach so understood, both the overall public budget for health care, as contrasted to other general programs, like defense, education, and other forms of transfer payments to the poor, and the proportion of the health care budget directed to the treatment and care of particular groups of patients, is fixed by comparing the contribution funds spent on health care, or on the treatment of one group of patients, make to the general welfare with the welfare benefits of those funds spent some other way. The approach would therefore direct public medical expenditure mainly to those who can be treated relatively inexpensively, to those who, if they recover, will provide more wealth or other value for the rest of the community, to those whose life is likely to be longest prolonged and enriched by medical treatment, and to those whose general quality of life and mental argument is such that the life they will lead if they recover is likely to be enjoyable and full of interest. The British scheme of distributing scarce health-care resources like expensive diagnostics, renal dialysis and transplant surgery under the National Health Service is a roughly utilitarian cost-benefit scheme. (It is interesting, and pertinent to the problem of senile dementia, that the British use age as a rough rule-of-thumb proxy for these other factors. Renal dialysis is generally denied to those over 45.[26])

Victims of serious and permanent dementia, particularly elderly victims. would fare very badly in that welfare contest. No treatment will make them useful to the community, they are not likely to live long in any event, and, though custodial care can relieve pain and anxiety, it cannot dramatically improve the quality of life of the seriously demented. (Any policy based on utilitarianism will for that reason work to the disadvantage of the elderly demented, and the disadvantage is aggravated by a fact we noticed earlier: that utilitarianism treats all interests as experiential, and therefore recognizes the dignity of the demented as a value only so far as they perceive and suffer from indignity.) So the cost-benefit approach to our problem would recommend a very low public contribution to the care of dementia victims, and perhaps none at all.

The welfare-floor approach justifies public provision for the handicapped on the ground that a humane society will not allow any of its members to sink below a certain level of well-being if they can be helped by communal support.[27] That approach seems less severe than the utilitarian cost-benefit approach, and more promising for the demented because, on any conception of the proper level of welfare below which a decent society will not allow its members to fall, the demented seem below that level: they are very badly off indeed. But they are in fact so badly off that the welfare-floor approach, paradoxically, may be of no more help than the cost-benefit one. For nothing can be done for people who are seriously and permanently demented that would bring them up to any reasonable minimum level of welfare that the welfare-floor approach might stipulate generally. Compare the way in which dementia victims might be treated under John Rawls influential theory that justice requires that the worst-off group in the community be made as well-off as possible.[28] If the worst-off group is defined in terms of welfare, for purposes of that theory, then dementia victims, together with other seriously handicapped people, might well count as the worst-off group. In that case that theory would recommend vast public expenditures on their behalf, continuing so long as any further expense would improve their welfare to however slight a degree. A community that accepted that principle would have very little resources left for any other purpose. Rawls in fact defines his groups in terms of resources rather than welfare, and he does not count the sick and handicapped (let alone the demented) as a social group badly off in resources just because of their illness or handicap. But his theory therefore provides no argument, at least as so far elaborated, that the sick are not entitled to special resources, beyond what others have, just in virtue of their sickness.

The welfare-floor theory is therefore of no help in fixing the right of a demented patient to public resources, unless it can be adapted by defining some level of support they are entitled to have short of the support necessary to raise them about some stipulated level of welfare or well-being. But there seems no way to define an appropriate level of support except by using some question-begging devices, by saying, for example, that the demented must be supported at a "reasonable" level of welfare. This is unpromising as well as vague, because nothing society can do will bring them to a level of welfare that is, on any plausible account of welfare, anything like "reasonable", and any society will bankrupt itself, as we saw in considering the implications of Rawls' theory, if it attempts to make their welfare as close to "reasonable" as possible. The failure of the welfare-floor theory suggests an important conclusion. Welfare is an inappropriate concept to use in defining the level of resources to be devoted to those whose welfare is low and cannot be much improved. Our conviction that something must be done for the permanently demented, in other words, is not a conviction we can usefully state as a concern for the overall level of their welfare.

The hypothetical insurance approach draws on ideas latent in the first three approaches we have now found wanting, though it is different from each of these. Its central claim is that people who become handicapped, including those who become demented, should be guaranteed the resources most people would provide for themselves, by way of insurance, if insurance were available to everyone on competitive and equal terms. (The philosophical basis of this idea is complex, and I offer some account of it in a long footnote.[29]) Suppose we can calculate, at least roughly, the insurance coverage the average member of the society, with average resources at his disposal, would purchase under those conditions, given the premiums he would in fact have to pay for each level of coverage he might choose. Under the hypothetical insurance approach, the government should collect taxes in the amount of the total premiums that would be paid for that insurance, and then use those taxes to provide that level of coverage to each person who does in fact become demented.[30]

If the calculations the hypothetical insurance approach requires can be made, it has obvious advantages over the other approaches I first described. Unlike the sympathy approach, it offers a strategy for fixing the amount of as well the general justification for a demented person's right to resources. Unlike the cost-benefit approach, it suggests that he has a right to substantial resources. Unlike the welfare-floor approach, it suggests that that right is limited, and is not a right to all the resources the community has. Its design insures, in fact, that the community can sensibly afford any provision it recommends, because it recommends only a total level of provision that members of the community, given all the other demands on their resources, could and would provide for themselves. It gives crucial effect, in designing the dementia-care budget it endorses, to the dominant values and wishes of the community, because these are reflected in the hypothetical insurance transactions that it contemplates. Its results are sensitive, as any rational policy should be, to costs and technology and to changes in these, because these hypothetical insurance decisions would be sensitive to the changing value and cost of new medical and institutional techniques for treating dementia and caring for the demented.

Nevertheless there are also obvious objections to the hypothetical insurance approach, and we must distinguish and then consider three of these. The first calls attention to the risk of errors the hypothetical private insurers might make, about their own interests, in the hypothetical insurance decisions the approach contemplates. The second notices important externalities to those decisions: it argues that the insurance decisions of private citizens will not take adequate account of the interests of the community as a whole in how its demented citizens are treated. The third objection is more profound and philosophical, and will require us finally to consider the long-postponed assumption I conceded was necessary to a great part of the argument of earlier sections of the essay. It suggests that the hypothetical insurance approach is unfair, in the special circumstances of serious permanent dementia, because the competent person who hypothetically insures is not, in the appropriate sense, the same person as the demented person whose fate is made to turn on the amount of insurance the insurer buys.

I shall consider these objections in turn, though allowing much more space to the third than the first two. I shall use the objections, moreover, to fill out my view of the likely consequences of applying the insurance approach to dementia, and I make use of my earlier arguments about the best interests of people who become demented for that purpose. I assume, then, that people believe that their experiential interests will be relatively unimportant once they become demented, and that their evaluative interests are mainly negative. They prefer to live as short a time as possible, once they have become permanently and seriously demented, but think it important not to suffer indignity so long as they do live. On these various assumptions, people would purchase only enough insurance coverage to provide minimum conditions of dignity, and would not seek to provide funds, at the greatly increased premium charges that would require, for life-prolonging medical treatment. If the insurance model survives the objections I consider, and others that might be brought against it, the rights of a demented person to resource for his care are therefore limited to that coverage.

C. Will Insurers Mistake Their Own Interests?

The hypothetical insurance approach limits a demented person's entitlement to the insurance it presumes he would have bought if offered the chance when competent. That limitation seems fair, because it seems to be in each person's antecedent interest. Suppose a young and competent person, full of desires and projects, is offered a range of insurance policies providing funds in the event that, when he is old, he becomes demented. These policies vary in the funds they provide, but the larger the coverage the greater the premiums and therefore the greater the sacrifice someone choosing the policy makes in his ability to lead the life he wants now. The hypothetical insurance approach assumes that an insurer would make the choice that, at least in his opinion, best reflects his interests overall. If he buys only a cheap policy which provides little coverage he has judged that it is not in his interests to spend the additional funds now to guarantee more resources if he becomes demented later. If the community disregards that decision, and taxes him more now to provide him with greater coverage if he does become demented, it contradicts the judgment about his best interests he himself has made, which it would be wrong to do. That is the argument at the heart of the hypothetical insurance approach.

The first objection I consider insists that this argument gives too much credit to each insurer's own judgment; it warns that he may cheat the old person he will become. That is, of course, a misleading description of the danger, provided the assumption I am making and will shortly defend is sound: that the young and the old person are different stages of the same person. It is more accurate to say that the young person will make some sort of mistake about his interests later, that he will exaggerate the importance of his present interests and concerns to his life as a whole, and correspondingly short-change the interests and concerns he will have later, if he does become demented. He may not appreciate, for example, how bad it is to be demented, or not realize how much he will want expensive custodial care then. The insurance approach, the objection insists, is too unforgiving of these mistakes. It holds someone to the decisions he makes when young even though he regrets these when he has grown older.

There are sound and important cautions in this objection. If we accept the hypothetical insurance approach, and speculate about how much insurance people would in fact buy at different stages of their lives, we must of course suppose them to have available, when they make that decision, as much and as accurate information as is reasonable, and that information should include knowledge about the actual manifestations, prognosis and circumstances of serious dementia. And we know that people do make mistakes about their own interests in the far future, even when fully informed, and often regret the decisions and choices they made in the distant past. That is one of the reasons why pensions and other forms of saving and insurance are often made mandatory: employees are not permitted not to enroll in their company's pension scheme. But once again dementia raises very special problems, and we need to consider, in order to assess this objection's force, the kinds of mistakes people might make in thinking about what their needs will be not merely when they are old but when they are demented as well.

We worry not that they might in some way exaggerate these needs, or the funds necessary to meet them, but that they will ignore or minimize them. Suppose therefore that a young person, asked to insure against dementia, makes the insurance decisions I am now assuming most people would. He argues to himself in the following way. "I will have two kinds of interests at stake if I become demented: experiential and evaluative. I now believe, on what I think the best evidence available, that the quality of my experiences will in any case be very limited. It is important to me, now, that I not be in great pain then, but not important that I have somewhat more of the thin and disconnected pleasures demented people can have, and in any case not important enough to sacrifice full-bodied experiences or plans now. I do have evaluative interests in not living in indignity, or being a burden to others. But I have no evaluative interest in living a longer life when demented, or having my life prolonged by expensive medical care. So I will buy only enough insurance to provide funds for the relief of pain, and for the most minimal institutional care in clean dormitory conditions." I shall call this the "minimal" argument because it justifies only a relatively inexpensive insurance policy, compared to a policy that would provide more elaborate custodial care and more extensive medical treatment. What sort of mistake do we worry that someone who accepts the minimal argument might have made?

In the more ordinary case, when people consider buying pensions against retirement, the young and old interests being compared are roughly the same kinds of interests, and if someone buys no pension we believe him to have made a mistake because his only reason for denigrating the latter is that they are postponed. But the minimal argument does not simply choose between interests regarded, time apart, as on a par. It characterizes the interests in play as different in quality and importance, and makes an overall judgment that the constitutive evaluative interest everyone has, in leading as good a life on the whole as possible, is best served by the distribution it chooses. So the mistake, if any, is not the predictive mistake characteristic of judgments about experiential interests, but the more philosophical mistake of judging fundamental evaluative interests wrong. What reasons might we have for thinking that the evaluative judgment of the minimal argument _is_ in fact a mistake? When someone is seriously demented he cannot regret his past decision to buy only limited insurance, and that is not an unimportant point, because one's desire not to regret is a significant experiential interest. Suppose, however, that a demented person could and would regret that decision. Would that show that the decisions was wrong? We must distinguish genuine regret, which requires a belief that we should have made a different decision, from a mere desire not to have consumed something in the past we would like still to have now. I would now prefer to have spent much less money in restaurants in the past, but that does not mean that, in the important sense, I regret doing so, that I think it was not in my own overall interest, judged then, to have acted as I did. But suppose the demented person were capable of regretting, and did regret, the minimal insurance in the genuine way. Since the judgment being regretted is a judgment of evaluative rather than experiential interests, it does not follow that it was a mistake. He may be wrong now rather than then.

We may put the point I am making another way. There is a kind of paternalism involved in the now familiar practice of requiring people to make some provision for their ordinary old age. We justify mandatory pension schemes by supposing that people do not attend in the right way to their ordinary interests in the distant future. But this paternalism is not very deep, because it does not contradict peoples' evaluative judgments, but rather enforces the very popular view that pain and distress are not less important when they happen in the distant rather than the immediate future. The paternalism that would be involved if we did not allow people to accept the minimal argument, and to purchase minimal insurance against dementia, is very different. This would, by hypothesis, contradict widespread evaluative judgments. We might be willing to accept the deep paternalism of that contradiction if we had reason to think the minimal argument obviously or even very wrong. But on the contrary, the discussion of a demented person's right to beneficence, above, supported that argument. So the first objection to the insurance approach, that it allows people to misjudge their own interests, must be rejected.

D. Does the Insurance Approach Cheat the Community?

The second objection is untouched by this reply to the first, because its focus is the interest not of insurers one by one but of the society as a whole. It argues that the decisions of insurers, about their own interests as individuals if they become demented, will not adequately reflect social interests that must somehow be accommodated; it is an argument, in other words, from what the economists call the externalities of private transactions. Assume that the minimal argument I just constructed proves very popular, so that a community guided by the hypothetical insurance approach collects only enough by way of taxes to finance a program of caring for the demented that denies them life-prolonging medical treatment, and allows them only conditions of minimum comfort and attention compatible with their right to dignity. The present objection complains that this program is unacceptable, not because it is not in the best interests of people who will become demented, but because a decent society cannot and will not tolerate that kind of care for its mentally ill. The great bulk of competent citizens, and not just the family and friends of demented patients, will feel outrage, and believe that their own humanity has somehow been compromised. They will insist that it is outrageous to deny life-saving medical treatment just on the ground that the life that would be saved is an undistinguished life. So the community will insist on providing more care than the hypothetical insurance approach would justify, which demonstrates, according to this objection, that that approach to the rights of the demented is flawed.

Should a decent society insist on providing life-saving treatment to everyone whose life can be saved? We have no difficulty in finding popular arguments that it should. Many people appeal to what is called the "sanctity" of life. Some doctors, for example, insist that any relaxation of their normal responsibilities to save life whenever possible would weaken the fierce and combatative professional instincts that force doctors to the limits of their energy when life is in the balance. They believe that weakening the taboo-like quality of that instinct, by recognizing nice exceptions, would damage the complex fabric of medical ethics woven around it. That argument can be generalized: many people feel that a society that does not unreflectingly insist that life be saved whenever possible cheapens the value of life generally and is more ready to decide against it in other contexts.

These may or may not be good arguments in favor of not relaxing normal medical practice when the patient is demented. Good or not, they appeal to social value and not to the good of the patient himself: they are arguments, if my earlier suggestions are sound, for sacrificing the good of the patient to the moral integrity or safety of the community generally. The insurance model, among its other virtues, captures that distinction. It is meant only to define the rights of the demented to resource, and limiting their rights to the resources they would have provided themselves, in hypothetical insurance transactions, in no way prohibits the community from supplying more in what it takes to be its own distinct interests, or out of its own moral compunction. So the second objection is not, after all, an objection to using the insurance approach for the purposes for which it is meant, so long as we do not make the mistake of thinking that the community is barred from spending more on the demented than they have a right to have spent on them.

The objection does, however, provide an opportunity to consider an important question about the insurance approach that I earlier postponed.[31] If we accept that approach in principle, should it be used to finance the care, to the level of resources it fixes, only of those who cannot afford that level of care themselves? In that case government would collect, in general taxes, only enough for that purpose, and those who have adequate resources in their own savings or, perhaps, in the savings of relatives, would be required to spend these before turning to society to make up any shortfall below the social provision. Or should the insurance approach be used to finance the care of everyone to the minimum level? In that case a tax structure would collect enough for that purpose, and everyone who becomes demented would be entitled to the minimum provision whether he could afford to pay for it himself or not.

There has been a long and complex debate, among those who generally favor social provision for the sick and handicapped, whether that provision should be needs-tested, that is, available only to the poor, or provided to everyone without reference to other resources. Our answer to the second objection is pertinent to that debate in the following way. The insurance approach argues for a general, non-means-tested program for the care of the demented, if society insists that more be spent, for their treatment, than would be justified on the insurance approach. Suppose the community insists, for the kinds of reasons we have just been canvassing, that expensive life-prolonging treatment must be supplied to anyone who is demented and wants it, or at least to those who did not provide, when competent, that it should not be used for them. If hypothetical insurance calculations show that that policy is not in the specific interests of people who become demented, who would choose, in advance and considering their own interests alone, not to provide for such treatment, then it should not be charged to their account when they are demented even if they can afford it then. The interests served by the policy are, by hypothesis, social interests only, and society should pay, out of general tax revenues, for what it wants or believes it needs or believes it moral integrity requires.

We can, I believe, generalize this argument so that it shows why society should assume responsibility, not only for life-prolonging medical treatment, but for the full custodial care of all demented patients. We have been assuming, in our discussion, that insurers would recognize that it is not in the interests of people who become demented to have their lives extended by medical treatment, and that insurers would therefore not pay the premiums necessary to provide such treatment for them.

People who do recognize this are also very likely to accept that it would be in their interests, if they became demented, to be killed as quickly and painlessly as possible. Suppose there were an insurance market for dementia in which insurers have the option of providing that they should be killed if they are judged, by an appropriate committee of competent physicians with proper safeguards, to be permanently and seriously demented. In that market a policy would be available, for people exercising that option, that provides only enough funds to pay for the administrative costs of the decision and the medical costs of carrying it out. That policy would be very inexpensive. Suppose that, in these circumstances, most people would exercise that option and choose that policy as the strategy in their own best interests overall.

In fact the option just imagined would not be possible in the United States, at least for the foreseeable future, or almost anywhere else. It is ruled out by the collective opinion that it is intolerable deliberately to kill even seriously demented people. People would vote collectively against a program of deliberate killing in spite of the fact that many, at least, would want to be killed themselves if they became demented. When they consider a general program of killing the demented, they focus on their own potential responsibility as killers, or as people who live in a community that kills: they think that no one could or should bring himself to kill another innocent human being, and they would not want to live in a society of people who would be willing to do that. That sense is much stronger, among us, than the different conviction I said some people have, that we must always seek to prolong life. Our moral traditions draw a firm distinction between "killing" and "letting die", even though many philosophers find that distinction untenable. Some people approve, in principle, of voluntary euthanasia: they think it would be permissible for a doctor to kill a terminally ill person in pain, for example, if that person then had a settled and informed desire to die.[32] But voluntary euthanasia, so defined, is not a possibility for the seriously demented who are incapable of informed and sustained wishes of that sort, and most people would be horrified at the idea of deliberately killing a demented person who says he wants to live, even if he had asked, when he was competent, to be killed in that situation. They think that deliberate killing of even the most seriously demented would do irreparable damage to the "sanctity of life" instincts I described earlier, instincts they think indispensable to civilization.[33] Refusing to honor an earlier, competent wish to be killed is not a violation of precedent autonomy. It is a violation of my autonomy not to allow me to kill myself, but autonomy does not include a right to be killed by another.

So the policy I am supposing a great many people would prefer — a very inexpensive policy contemplating that the insurer will be killed — is not in fact one of the possibilities. Insurers would only have available, and we are now supposing would mainly choose, the minimum policy I described earlier, which does not provide funds for life-prolonging treatment, or comfortable custodial care, but does meet the minimum requirements of dignity. That policy defines, on these assumptions, what demented people are entitled to have. But the fact that the much cheaper policy that contemplates being killed is not available, though it would be in the interests of many people who might become demented to choose it if it were, provides a strong argument that society should make that minimum level of care available to all those who become demented, even those who have the resources to provide it for themselves. I do not mean to be relying, in making that claim, on any assumption that people have a general right to be compensated when they are denied opportunities that run against social interests or that would offend sound moral principles. Plainly that is not generally true: I have no right to compensation when I am not permitted to use my property in a way forbidden by sensible zoning restrictions, for example, or in an immoral way. But the case of dementia seems special in this context also.

People who have become demented have lost control of their lives: their important evaluative interests are at the mercy of others, and if the community takes some decision that cuts strongly against those interests, the demented person can do nothing to repair the damage it has done. A competent person who believes it much in his best interests to die can usually kill himself whether or not others help him. A person who has become demented, therefore, is specially damaged when we refuse to help him by appealing to our own, competing interests and principles, and we ought to minimize the damage if we can. When he was competent, we are now assuming, he would have preferred being killed if he became demented to having whatever property he has then used to support him. He would have preferred, perhaps, that that property be available to his family. If we decide that we cannot honor his overall preference, in virtue of our unwillingness to kill him, we should at least try to give him as much control over his life as we can.

If the community limits its program of taxation for the care of the demented to those who cannot afford the care it would provide, and private insurance providing that level of care is not available, on comparable terms, for the rest, then someone of adequate means has not been allowed to protect his family in the way he would have chosen to do. So we have that reason for making the public program a comprehensive one, and no reasons of comparable power against this. A comprehensive program would not, after all, increase the total expense to the community of caring for the demented. It rather distributes the same total cost over all citizens, those who do and do not become demented alike.

E. Insurance and Personal Identity

The third objection in our list challenges the hypothetical insurance approach in a more fundamental way than the first two. It denies that a dementia victim is, in the sense the insurance approach requires, the same person as the person occupying his body earlier who purchased, as we are now assuming, insurance providing for the victim's care. Of course, in a perfectly familiar and idiomatic sense of identity, a demented person is obviously "not the person he was," just as someone whose personality has changed less dramatically, or who becomes suddenly more vigorous, is often said to be "a new person". That idiomatic expression is not meant to challenge the continuity of what the philosophers call "personal identity"; it is not meant to suggest that someone suddenly more vigorous is *actually* a different person, in the much more fundamental sense in which one twin is a different person from the other no matter how alike they are in personality. We assume, on the contrary, that any particular person remains the same person in that fundamental sense -- that the life he leads is a single life -- from birth to death, even though both his body and personality change dramatically between those two events. The insurance approach presumes that this normal assumption holds even when this putatively single life is punctuated by irreversible dementia.

It assumes personal identity in two ways: it assumes that the insurer who buys a certain level of coverage for his care when demented acts out of what he takes to be prudential concern, and it assumes that the dementia victim is bound by the insurer's decision because his life is part of the same temporally co-responsible life as that of the insurer.[34] The first of these assumptions is familiar in ordinary life. Normal people have a special, forward-looking concern for themselves, which we call prudential concern, that is different in character from the concern they have for other people in general. Prudential concern need not be, as this contrast might suggest, selfish in the ordinary sense; everyone, not just people indifferent to the needs or claims of others, is distinctively concerned about himself, about both his own evaluative and experiential interests. People characteristically distribute resources available to them in two ways or at two levels. They make distributions between themselves and others, deciding how much of what they have should be devoted to the good of other people, who may be strangers or people to whom they are specially attached by blood or affection. But then, with whatever is left for them, they must make prudential distributions over their own lives, deciding, for example, how much to consume now or soon and how much to save or invest for the future. The insurance approach assumes that the decision someone makes insuring against later disease is a prudential decision of that character: it assumes, that is, thát someone who pays a particular premium for a particular level of coverage for later illness has made a judgment that spending either less or more for insurance would distribute resources within his life as a whole in a less satisfactory way.

The second assumption — the assumption of temporal co-responsibility — is the backward-looking correlate of prudential concern. It is a moral assumption, about the special connection between events in one stage of a person's life and what he is entitled to have, or how he is entitled or deserves to be treated, at other stages. We rely on temporal co-responsibility when we suppose, for example, that someone who has been given more resources than others have early in his life is for that reason entitled to less than them later, even if he has consumed rather than saved those extra resources. We also rely on it in almost every moral or legal judgment we make about ourselves and others: in our judgments about property, guilt, shame, pride, punishment, reward, respect, and integrity, for example, and also, though perhaps in a somewhat attenuated way, in our emotional assignments of love, friendship, community, jealousy, resentment and hatred.[35] These various judgments and emotions presuppose that, though we may think of our lives as divided into temporal stages, these stages are mutually co-responsible in the strong sense that each stage must share responsibility for, and adjust its claims of entitlement and desert to take account of, what other stages have done or will do. That assumption seems necessary if we think it fair to make a patient's insurance coverage depend on the prudential decision of the insurer, typically made many years earlier.

I do not mean that we insist on enforcing temporal co-responsibility in all circumstances. We think that that would sometimes too stringent, because, as we say, people should not always be held to imprudent decisions, particularly those made much earlier, or blamed or punished for mistakes made long ago.[36] Indeed, our sense that it would be wrong to do this contributes to our willingness to accept certain paternalistic constraints of the kind we noticed in discussing the first objection to the insurance approach. We insist that employees contribute to a pension plan because, among other reasons, we think not contributing would be a mistake that it would be wrong, as well as inefficient, to hold people to when they are old and retired. The hypothetical insurance approach, applied to dementia, assumes, however, that we have no reason to relax temporal co-responsibility between the dementia victim and the insurer on any grounds of that sort, and I tried to support that assumption in my reply to the first objection.

Are the connected assumptions of prudential concern and temporal co-responsibility really essential to the insurance approach? Suppose someone suggested that public provision for a dementia victim should depend on what insurance someone who was obviously a different person — a relative or a stranger — would have purchased, in a hypothetical insurance market, providing for that victim's care. We would find that bizarre. The designated relative or stranger might have bought no insurance for that purpose at all, preferring to use his resources for his own benefit than to provide insurance for someone else. It would not follow that the victim should have no funds available to him. Or the stranger, out of altruism, might have purchased extravagant insurance, cheating his own life to pay the premiums. That does not matter either: the insurance approach argues that someone should have, for his care, not the amount that might have been provided for him in some way had the past been different, but that he would have provided for himself out of prudential concern, that is, out of a judgment that his evaluative and experiential interests would be best served overall by distributing his resources among different parts of his life in that way. So the insurance approach does seem to depend on the plausibility of the two assumptions I have been describing: that the hypothetical insurer decides out of prudential concern, and that hypothetical insurer and the patient are temporally co-responsible in the way different stages of the same person are. These two assumptions in turn seem to require -- it might be better to say that they seem to constitute — a further assumption, that the hypothetical insurer and the patient are the same person, that is, that dementia does not destroy personal identity. And I have taken pains, throughout this essay, to identify other ways in which our judgments about the rights of people who have become demented also seem to require that assumption about personal identity.

VII. The Identity of Persons

A. Two Continuities

Is the assumption I have been making, that dementia does not destroy personal identity, sound? Even serious disease does not normally destroy personal identity. Someone obviously remains the same person after he becomes cancerous or contracts pneumonia. But in the special case of serious and permanent dementia, survival of personal identity might well seem more problematic, for the following reason. In the normal, unproblematic cases, the later stage of what we unhesitatingly assume to be the same person is continuous with the earlier stages of that person in two ways. The stages are *physically* continuous: the state of the physical body each stage inhabits is the product of a series of changes in the body earlier stages inhabited, and none of these changes is itself sufficiently great to regard the body it produced as a new one. The stages are also *psychologically* continuous: the belief, convictions and projects each stage has are in the main those of an earlier stage; changes in these beliefs, projects and convictions are mainly themselves guided by other beliefs, projects and convictions held constant, so that mental life develops, in Otto Neurath's famous image, like the repair of a boat, one plank at a time, at sea, and the various stages are sewn together by overlapping experiential memories.

Dementia does not destroy the first kind of continuity — physical continuity. Though the various diseases that produce dementia have a physiological basis, and most of them produce important changes in brain structure, these changes are not more radical, judged simply as physical changes, than amputation of a limb or other changes no one would think made a body a different body. But the second continuity -- psychological continuity -- is indeed destroyed in serious and permanent dementia. Someone seriously demented loses intellectual and emotional continuity with past stages of "his" life. He suffers total disintegration of personality, so that none of the beliefs, convictions and projects he may have can any longer be seen as mainly fixed by earlier ones, and he has total amnesia of prior experiences, identity, and attachments.

Are both forms of continuity essential to preserve personal identity? If not, is one or the other essential? Which one? There is an extensive, ancient and enduring, philosophical literature on exactly these questions. Philosophers disagree, as we shall see, about whether personal identity over time depends on physical or psychological continuity. They debate this question largely by puzzling over enormously unrealistic science-fiction examples like this one. Suppose all A's beliefs, convictions, memories and so forth are in some way drawn out of his brain and transferred to the brain of B, and B's beliefs, etc., are in turn transferred to the brain of A. If physical continuity is necessary and sufficient to personal identity, then the person in A's old body is still A, though he now has all B's former beliefs and memories.[37] If psychological continuity is necessary and sufficient, then the person in A's old body is now B.[38] If both physical and psychological continuity are necessary, then both A and B have disappeared, and the people inhabiting their former bodies are wholly different people. If either of the latter two views are right, then the normal assumption, that personal identity is preserved in spite of even serious disease, would fail for the case of dementia, and the hypothetical insurance approach to public provision for dementia victims would be undermined. We should then have to find some other device or principle or theory on which to construct an argument fixing and limiting the entitlement of the demented to communal resources, and also other arguments different from those I used earlier to decide whether demented people had any rights at all and, if so, what rights they had.

B. Does Identity Really Matter?

It therefore appears that we must puzzle over the vast philosophical literature I mentioned, to decide whether physical or psychological continuity, or both, are required to preserve personal identity over time. Many people, however, would think it absurd that an important practical issue of social justice, like the issue of public provision for the care of dementia, could depend on arcane philosophical problems of that sort. How can it matter so much whether it would be right, as a matter of accurate use of language, to say that a dementia victim is the same person as the former inhabitant of his body? One contemporary philosopher, Derek Parfit, argues, supporting that instinct, that personal identity is not after all what matters when issues of personal or political morality are at stake.[39] It is worth pausing, therefore, to consider whether we can use his arguments to disentangle the practical question, whether the hypothetical insurance approach is sound in the case of dementia, from the mysteries of personal identity.

Parfit argues his claim, that personal identity is a matter of little real importance, through a series of examples, in which the following imaginary exercise is crucial. Suppose that all my cells are destroyed but simultaneously new, identical cells are created in some distant place, so that a replica then exists there who has exactly the same physical attributes, memories, emotions, attachments, and so forth that I did. Is the replica then me, in a suddenly different place, or not? Orthodox theories, Parfit believes, suppose that a great deal turns on that question. If the replica is still me, according to these theories, then I have survived the experiment, and have nothing to regret; on the contrary I should be happy to have traveled so quickly. But if the replica is not me, then I have died, and this is, for me at least, a tragedy. Parfit argues that it is implausible to suppose that so much could turn on the decision. When we know the ordinary facts — that the cells are identical, that memories are preserved, and so forth — we know, he says, everything there really is to know. The question whether we should count the new body as my body, he says, is only a question of classification, like the question whether we should count France as the same country it was, say, a century ago. He believes that the better classification scheme — the one he thinks we actually use — provides that the new body is not me, but someone else I might call Backup. I have died, but the situation is not significantly worse, for me, than if I had survived. The connections I have with Backup are the same, in all important respects, as those I would have had with myself if the transformation had not taken place.[40] If I had just died, and no one existed like Backup, the situation would certainly be much worse for me. What makes the difference is not my failure to survive, which holds in both cases, but the fact that someone connected to me in all important ways does survive in one case but not the other. If follows, Parfit argues, that identity is not important. What is important is the matters of ordinary fact, about psychological (and perhaps physical[41]) connections, which we can describe without making any assumption, either way, about the issue of identity.

We must try to apply Parfit's argument to the hypothetical insurance approach, to see whether we can free that approach from the assumptions about personal identity I argued it required. The following strategy suggests itself. I said that the insurance approach presupposes both prudential concern and temporal co-responsibility, and that these in turn presuppose personal identity. We might now question the second of these claims. Perhaps we can show that prudential concern is appropriate, and temporal co-responsibility justified, when certain psychological or physical connections hold whether or not we count these connections as either necessary or sufficient for personal identity. Then we can decide whether the hypothetical insurance approach is justified in the case of dementia by asking a normal question of fact — whether whatever connections we decide are necessary for prudence and co-responsibility in fact hold in serious and permanent dementia — without having to puzzle about personal identity after all.

Parfit suggests that we should decide which connections between a person and his putative survivor are important by considering which connections would matter to a person contemplating some event that calls identity into question. So we might begin, looking for connections that justify prudence and temporal co-responsibility, by asking that question about people contemplating insuring against dementia: which connections would they think important? But we must now notice an important distinction between two ways in which someone might regard any particular connection between himself and the survivor of some experiment or event as important. It might be important to him that someone who is connected to him in that way survive the experiment, important, that is, that someone so connected to him continue to exist. Or it might be important to him how the life of someone connected to him that way goes, how good a life that is.

These are plainly very different matters, as we can see by reflecting on Parfit's examples of why it might matter to me that my Backup exist when I no longer do. It might matter to me, Parfit explains, because Backup, having the same projects and attachments as I do, would be likely to finish my book, care for those I love, and so forth. But if those are my reasons for wanting Backup to survive, they give me nothing but an instrumental concern with Backup's welfare; they give me, that is, no reason to care about Backup's well-being, about the overall value of his life, about whether he is happy or miserable or able to carry out new projects he develops for himself; indeed I would want Backup to be less happy, and less busy with his own new projects, if that would make him more likely to devote himself exclusively to my books and concerns.

Parfit is right in supposing that the first of these questions -- whether it is important to an insurer that someone survive with the connections to him a dementia victim has -- may be answered independently of any assumption about whether the insurer and the victim are the same person. If the insurance approach presupposes an affirmative answer to that question, however, we must reject that approach. Most insurers would give that question a negative answer. Most people, as I said, would in fact prefer death to survival in that form, and the few who would prefer survival would not much prefer it. But the first question is plainly not the question on which the plausibility of the insurance approach turns, because it is not the question made pertinent by the assumption of prudential concern. Prudential concern requires that the connection between the insurer and the victim be important to the insurer in the second way, that it matter to the insurer not whether someone in the condition of the victim survive but what happens thereafter to the victim, how his life goes. It requires, moreover, that this matter to the insurer in a certain way: prudentially. Otherwise the insurer's decision to buy or reject insurance would not be the distributive decision, among stages of a single life, that the insurance approach presupposes. Those who would prefer to die than to become demented do have that kind of concern: they believe that the demented person is, in the phrase normally used, better off dead, and would prefer him dead, not out of indifference for his fate, but on the contrary out of prudential concern for it.

Their concern, in other words, seems to involve the assumption we are hoping to avoid in describing the connections necessary to make prudential concern appropriate: they assume that the demented stage they worry about is a stage of their own life.

So we have not succeeded, after all, in distinguishing the question about which psychological or physical connections are vital for prudence and co-responsibility from the question about which of these connections are essential for identity. For an insurer has to answer the second of these questions (or assume an answer to it) in order to answer the first. We encounter the same difficulty, though in a different form, when we concentrate on the second assumption on which the insurance approach depends: the assumption of temporal co-responsibility. Our strategy requires us to identify the kinds of connections that must hold, between an insurer and a victim of dementia, in order to justify our assumption that provision for the latter may fairly be made to depend on decisions made, and resources consumed, by the former. At least when psychological continuity has been destroyed, the only connection that could justify that assumption is the connection of identity itself.[42] Suppose we believe, after having reflected on the philosophical issues raised by the problem of personal identity, that the insurer and the demented person are, in fact, the same person, that these are stages in a single life. Then it will seem right to us that co-responsibility should hold with respect to resources, at least. If the insurer acted out of prudential concern for the victim, and these are in fact the same people, why should the fact that the victim does not remember the insurance decision, or remember enjoying the benefits of money the insurer saved by not buying more expensive, make it unfair for others to be guided by that decision in providing care for him? Suppose, on the other hand, that we believe that personal identity does not hold, that the victim is not the same person as the insurer. Now it seems wrong, for that reason alone, to apply co-responsibility through the insurance approach. Then we can say, to someone sick and lacking funds, only that he would have been entitled to help if the former occupant of his body had had more altruistic concern for him, but that as that former occupant was indifferent to his fate, or too selfish to share resources with him, he must go without. He would rightly complain that, until we claim that the earlier inhabitant was him, we have supplied no reason why he should have less than another victim of the same disease who happened to share a body with a more generous antecedent.

The general point is clear enough. The assumptions of prudential concern and temporal co-responsibility are deeply connected, as two sides of the same coin, just because they share and depend on the idea of personal identity, the idea of a single life lived in stages each of which is co-responsible for the value and fate of the whole. They are, as I said, not so much consequences as aspects of personal identity. All the judgments we make, about rationality, prudence, and fairness as well as all the other judgments we make about persons, are tied together in a scheme woven around and through personal identity. So we cannot conclude, as the strategy I constructed from Parfit's argument hoped to conclude, that personal identity does not matter for the insurance model.

We are considering whether the two assumptions, about prudence and co-responsibility, which that approach requires are sound in the case of dementia, and for that issue the connections between and insurer and the victim he becomes matter only if, and then because, they constitute identity. Identity, for our present problem, seems to be all that matters.

I want to guard, however, against a misinterpretation of my argument. I do not mean to contest Parfit's claim that decisions about personal identity are at bottom a matter of classifying facts about connections rather than adding a further fact to them. In the next section I try to explain the sense in which problematic decisions about identity, in bizarre and speculative cases, are indeed classificatory, and why it is nevertheless sensible to treat these decisions as having the great force I claim for decisions about identity in the context of dementia. The argument of this section itself suggests, moreover, an important virtue of Parfit's general approach. Arguments and issues about personal identity are indeed usefully seen as arguments about connections between stages of a person's life rather than about some metaphysical fact in some way independent of those connections, and that is important in deciding what kind of philosophical issues puzzles about identity raise. But the crucial connections in point are not what we might call, in this discussion, the brute physical and psychological connections on which Parfit's discussion concentrated, but rather the more morally infused connections of prudence and co-responsibility we have been considering. We must aim, at least, at an account of personal identity that respects and make sense of these latter, crucial connections.

C. When Am I Still Me?

I said, before we turned to Parfit's claims, that orthodox theory divided about whether physical or psychological continuity, or both, are essential to the kind of personal identity the insurance model requires. What kind of question is this? What would count as a good argument on one side or another? We need some distinctions to confront this threshold issue. Is personal identity properly understood as an "independent" or a "supervenient" fact? I must explain the distinction I have in mind. Imagine two people, A and B, each of whom undergoes exactly the same science fiction transformation; each of whom, for example, is simultaneously extinguished and fully-replicated, in exactly the same way, to produce A' and B'. Is it conceivable (whether or not physically possible) that A and A' are the same person, but B and B' are not? If so, then personal identity is an independent fact that might conceivably happen to hold in the connection between A and A' and not in the otherwise identical connection between B and B'. If not — if that is conceptually impossible — then personal identity is a supervenient fact: it holds in virtue of other facts and so cannot differ when these other facts are identical.

Some people are said to think that personal identity is carried in a soul. The problem of personal identity, for them, is a problem of deciding whether when A's cells are simultaneously destroyed and replicated, for example, A's soul sometimes or normally or always sets up shop in

A'. On that view of personal identity, identity is an independent (or, in Parfit's language a "further") fact. Puzzles about personal identity call for discovering, or at least speculating about, such facts. We must ask whether, on the assumption that souls always behave in the same way, they follow physical or psychological continuity or both or neither, and we assume this to be a matter of discovering what, as a matter of fact, the soul does faced with this sort of challenge. And we might well discover that, as it happens, the soul does not always behave in the same way, that it follows psychological continuity in some kinds of cases -- brain bisections, for example -- and physical continuity in others, like dementia.

Most philosophers who write about personal identity do not think it plausible that personal identity is in that way a matter of independent fact. They assume that personal identity is a supervenient fact: identity exists, when it does, in virtue of the connections that, on this view, constitute identity. The problem of personal identity is then not a matter of discovery in the normal sense; we do not look to see whether personal identity, as things fall out, follows one kind of continuity in one kind of case and a different kind in others. Instead we reflect on whether personal identity follows from or is constituted by one rather than another kind of continuity. But what kind of reflection is this? Again, two views are available, and must be distinguished.

They begin in different stories about the way judgments about personal identity function in our everyday lives. On the first, or formula, view we make these judgments by applying some shared general rule or formula, of which we are not fully aware, that for us defines the concept of personal identity. Philosophical reflection, on this view, aims to help us discover what that hidden rule or formula actually is: we ask what formula explains the various judgments we actually, unreflectingly, make. Once we have discovered the formula, in that way, we can then use it to solve problematic or controversial cases, like, perhaps, the case of serious dementia. On the second, or Wittgensteinean, view we treat our ordinary judgments about identity as deep, perhaps wired-in[43], assumptions that are presupposed, individually and socially, in the lives we lead, but that do not necessarily represent or answer to any general rule or formula. Puzzling or problematical cases arise, on this view, only when we imagine new possibilities, like those of science-fiction, that we have not confronted in our ordinary lives, and so have not captured in our ordinary, concrete intuitions of identity. We cannot solve these speculative cases by applying some latent formula or algorithm of identity we already have, because we have none. But we can reflect on them in a different way if we choose: we can try to assimilate them to more ordinary cases by asking how it would be best to reform or adjust or extend our ordinary, intuitive assumptions to embrace the speculative cases if that were for some reason necessary.

The majority of the philosophers who have written about personal identity seem to hold the formula view. They see the science-fiction cases they construct as crucial testing cases in the following way. In normal cases, when we unhesitatingly assume that a small boy of seventy years ago and an elderly man now are two stages of the same person, for example, too many formulae fit our assumptions. We would make the same judgment whether we held that physical continuity or psychological continuity or both constituted personal identity. So we need science-fiction cases to separate and test these different formulae. If we have uniform and unhesitating reactions to these cases -- if almost everyone agrees that personal identity either does or does not hold -- and if these uniform reactions to different cases support the same formula, then we can, in that way, discover the latent constitutive rules we are following unawares. But this procedure has an Achilles heel. It cannot tell us how to decide some case we find genuinely problematic. For the existence of any deeply puzzling case of that sort, when we simply don't know what to say, would be a counter-example to any formula that decided it crisply one way or another. The most a philosopher could say, in the face of a recalcitrant case of that sort, is that conceding (or denying) identity would be consistent with what we think and say in other cases. But that is not enough: since a great deal turns on whether we concede or deny identity, consistency in language is not in itself a central concern. That fact, indeed, explains the reaction I anticipated much earlier: many readers will find it odd that the appropriateness of the insurance approach to dementia could turn on whether normal linguistic practice warrants saying that identity survives dementia.

In any case the philosophical literature hardly suggests that we do have the uniform, consistent and unhesitating reactions to science-fiction cases that the formula view needs. Many people, confronted by the bizarre examples of the texts, are uncertain; those who are certain divide; and many of their opinions, certain or hesitant, are internally inconsistent. An elegant series of examples constructed by Bernard Williams is instructive. Imagine (he asks) that you are in the power of a villain who tells you that all your mental states — beliefs about yourself, memories, and so forth — are to be transferred to another body, so that the person in that body will think himself you. Then one of two bodies (your old body or the body now housing your mental states) is to be tortured, and you must choose which now, in advance. Which possibility do you dread, that is, hate in the prudential way: the villain torturing your old body or the body of the person thinking itself you?

Most people (Williams thinks) would dread the torture of what they would consider their "new" body. Each assumes, that is, that he has changed bodies, that he is the person inhabiting the body he did not inhabit before. This suggests that the formula underlying personal identity makes identity track psychological rather than physical continuity. But now (Williams continues) imagine this different case. The villain proposes nothing about transferring your mental life into another body. He proposes only, in a more old-fashioned way, to torture you, in an hour. Your prudential concern is certainly aroused: you dread what will happen. Then he tells you that just before your pain begins he will make you permanently demented: you will think yourself Napoleon and lose any memory of or sense of being the person you are. Williams believes that this new information will not eliminate or even ease your prudential concern. In fact, he suggests, you will think your situation worse than you did before you received this latest news, because now you believe that you will both go mad and be tortured. This (natural) reaction seems inconsistent with the (natural) reaction to the original mental-transfer-then-torture case, for it assumes that personal identity does not require psychological continuity after all, that mere physical continuity, in these circumstances, is enough to preserve prudential concern and therefore identity.

This argues, not that we have made some mistake we must correct in one or the other of our replies, but that our judgments do not answer to any formula framed in the vocabulary of necessary and sufficient continuities. So we do better to take up what I called the assimilationist view of the problem of personal identity. Our situation, on that view, is this. We live our lives on the basis of fundamental and unquestioned convictions fused together in the package of ideas we have been considering: that each of us is a person continuing over time with forward-looking prudential concern for later stages and backward-looking co-responsibility for acts and decisions made at earlier stages. This package of ideas includes, among much else, an account of the dimensions of life, that is, the period over which prudence and temporal co-responsibility hold. People's opinions about the exact dimensions of life vary from culture to culture, even from person to person. People who believe in a straightforward conception of a life after death, for example, which includes the idea that what happens to someone in Heaven properly depends on what he does during his life, have a different dimensional belief than people who accept no such idea.[44] Fortunately most differences in the dimensional beliefs members of a particular community may have do not significantly affect political decisions: the same rules about ownership and rights in property, for example, and the same assumptions about the plausibility of the insurance model, fit the dimensional convictions of all groups. So we share, and our political life depends upon, a more limited and public set of dimensional assumptions structuring prudential concern and temporal co-responsibility for public purposes. We agree, for that purpose, about what a basic life or "life on earth" is: we agree that someone's life, in this basic and shared sense, begins with the birth and ends with the death of his body.

I have been suggesting, since the early pages of this essay, that there is a serious problem about personal identity and dementia. I want now to qualify this suggestion: you will probably think there is a serious problem about identity only if you are persuaded to the formula view of that matter. On this Wittgensteinean view, there is no problem about the continuing personal identity of a demented person. It falls within the dimensional beliefs of our culture, and within our public dimensional settlement, that a single life may have a demented stage, which can be the last stage. My evidence is the unhesitating convictions I have been reporting throughout the argument, like the conviction many people have that they would prefer to die, quickly and painlessly, than to continue living demented. The formula approach, I now suggest, creates a problem about the identity of demented people, in the following way. It demands that we account for all the features of our natural and unhesitating opinions about identity by producing a formula. We then realize that a formula that fits most of the ordinary dimensional convictions — that personal identity is a matter of psychological continuity — fails for the demented. We are attracted to that formula in at least some of the science-fiction cases philosophers create, like Bernard Williams' first case, and we think worry that perhaps personal identity does not hold in dementia after all. But if we accept that the search for a formula is itself misguided, and take the assimilationist approach to the science-fiction cases, we have lost our reason for challenging the view we already hold, and the ordinary, common-sense view, that personal identity survives dementia, is unshaken.

Some readers, however, may not be as confident as I am about the common-sense status of that view: they may find themselves troubled rather than clear about whether personal identity does survive dementia, and think that this must be regarded as at least a hard case that, on the assimilationist view, calls for adjusting rather than simply applying the system of moral, political and metaphysical ideas in which personal identity figures. So it will be useful (and is anyway desirable as giving more content to the assimlationist view) to consider at least briefly how the process of assimilation might actually work, on that view, in genuine hard cases about identity. Truly bizarre or novel cases call for something extraordinary and unknown in ordinary life: a decision about the dimensions of life. Suppose replication became commonplace, and people actually began to "travel" by having their cells extinguished and replicas instantly created someplace else very far away. Our institutions and practices — of property, emotion and blame, for example — could not operate without personal and communal decisions: we should have to decide whether, at least for public and quasi-public purposes, prudence and co-responsibility hold between me and my replica. It seems plausible (and, if such cases actually arise, almost inevitable) that we would decide them so as to require the least adjustments in the ordinary, intuitive scheme of ideas we are extending to the new situation. That would require us to decide, I believe, in favor of identity in the travel-by-cloning case; indeed, we would already have reached that decision, perhaps without much worrying about it, I we took up that method of "travel".[45]

It is important that hard cases are not to be decided all at once, on the assimilationist approach, by settling on some new formula about necessary and sufficient continuities and holding to that new formula in all novel and bizarre circumstances. The issue is rather, for any new puzzle that actually arises, more practical and retail: given the character, point, and efficacy of the complex set of ideas woven around personal identity, is it all things considered better or worse to regard identity as continuing in these circumstances? We may, however, notice certain principles or rules of thumb which, while they may yield to countervailing considerations in some cases, nevertheless pick out important considerations we would expect to be very weighty generally. We should try to extend or adapt the ordinary dimensions of life, when this is necessary, with an eye to the efficiency and fairness of the public system of prudential concern and temporal co-responsibility. The efficiency of that system argues against what we might call *unconnected* lives, that is, persons whose rights and attachments cannot be traced backwards and forwards to the birth and death of a human body in the way our elaborate legal schemes of property, inheritance, and family assumes and the dense and complex pattern of emotional life I described earlier presupposes. Unconnected lives challenge these institutions and systems of judgment and emotion, and that is a powerful reason for extending our dimensional convictions, in the face of challenge, in favor of connection. Of course, under some circumstances enforcing that presumption for connection would be infeasible, because prudential concern would be unnatural and unstructured: someone told he must be prudent for the combination of himself and someone else, whose fate he cannot connect with the value of his own life, has no way to be prudent as distinct from altruistic. In other circumstances enforcing the presumption would be unjust, because temporal co-responsibility would be in some way unfair to portions of the experiences it yolks together (I shall offer an example of that kind of unfairness just below). So the presumption of connection, while powerful, cannot be absolute.

These reflections suggest the following rule of thumb. If stages of human experience are connected by either of the two main continuities -- physical or psychological -- then we should assume continued personal identity, for purposes of the twin assumptions of prudential concern and temporal co-responsibility, unless this would be irrational because prudence could take no hold or unjust because co-responsibility is unfair.[46] It does not follow, from this general strategic principle, that personal identity should always be denied when neither continuity is present:

we might (however absurd this now seems) find reasons for accepting the doctrine of reincarnation that would make it plausible to claim personal identity over what we now regard as entirely separate lives. And the test of "pointless or unjust" the strategy proposes is a relative test: we assume that the ideas of prudential concern and co-responsibility have some point, and are just, in the normal circumstances in which these constitute our lives, and the strategy requires us to ask, in some hard case, whether, given that assumption, that case is different from the normal circumstances in some way as to call these ideas into question there.[47]

The rule of thumb we are constructing supports what I believe to be already our view, that personal identity should be regarded as surviving even serious and permanent dementia. Physical continuity holds in that case. So we must ask whether there is any infeasibility or injustice in laws and schemes of provision, like the hypothetical insurance approach, which assume that personal identity holds as well. It is hardly infeasible for competent people to take up prudential concern for demented stages of what we propose to consider their later lives. When we considered the evaluative interests of people who become demented, in an earlier section of this essay, we noticed a large variety of ways in which people can and do display that concern, that is, ways in which they believe what happens to them when demented affects the character and value of their life as a whole. We cannot call these concerns irrational without indicting a great many other concerns competent people have. They do not presuppose any dubious facts, as, for example, a belief in reincarnation does, and they are closely related to other, familiar kinds of concern we do not regard as irrational. It is, for almost everyone, a matter of concern not only when they die but how they die. Some people think a peaceful death important, others a death in action, with their boots on, and others a death not of resignation but of struggle: one should not go gently, they think, into that night. People who would rather die than languish demented have, in effect, that further preference about the manner of their death. Almost everyone thinks, moreover, that what happens after his death can affect how good his life was on the whole. People think their lives have been more successful if projects they began are completed and prove valuable later, and they care about how they are remembered, about what image of them survives among those whose view of them matters. They also care about whether they are a burden to others, and to whom they are a burden. Many people hate the idea of growing old a burden to their children or to society, or of dying with debts others must meet, and these fears are surely not less rational when they are fears of burden when demented rather than incapacitated in some other way or demented rather than dead. All these various preferences, allied to or including dementia-state preferences, are firmly prudential preferences. They are special and vivid in the first-person: someone's views about how he should die are important to him in a way his views about how other people should die are not.

So we cannot regard the concerns people have for their situation when demented as irrational, unless we call into question a host of other, perfectly familiar, concerns of much the same character. We must therefore turn to the second part of the test our rule of thumb provides, which asks whether the assumption of co-responsibility would be unjust. We assume that in the normal cases, when people remain competent, it is not unjust to enforce property rules that make what someone has now depend on what he has spent in the past. Does that become unjust, for some special reason, if he has become demented in the meantime?

It might be helpful to design a fantastic case in which we would think that a certain assumption about personal identity is ruled out, on the assimilationist approach, because co-responsibility would be specially unjust. Consider another hypothetical that has occupied philosophers. Suppose all the cells of my body, including those of my brain, are divided, with the consequence that two human beings now exist with bodies identical to mine, and with exactly my memories and other mental life. I cannot be one but not the other because they differ in no way that could justify selecting only one as me. There would, I think, be no logical difficulty in regarding me as both, that is, as regarding my life as now having two independent branches. It would not be incoherent to suppose that if I had known, early in my life, that this operation was forthcoming, I should have had prudential concern for the two lives that would then begin, and that the fate of each of these lives should depend on what I had provided for them. But these requirements might well be thought unjust, because I would then have either to cheat my life before I was divided, in order to make available enough for two lives later, or these lives would have to share what would normally do for one. It is that kind of injustice, rather than any assumption that mere psychological continuity is insufficient to sustain personal identity, that provides the strongest argument, on the assimilationist approach, for denying that my life continues in the life of both replicas. There is no comparable injustice, however, in regarding a dementia patient as co-responsible with the insurer who earlier occupied his body. From the standpoint of justice, there is no difference between this case and the normal case: the fact that the dementia victim cannot remember being the insurer provides no reason of justice why his provision should not depend on the insurer's decision. The rule of thumb strategy would endorse most people's unreflective assumption, that personal identity survives dementia, even if we did regard this as a hard case rather than one already decided in the constitutive assumptions we already have.

Footnotes

[1] I do not mean to suggest, even in these sketchy remarks about rights that I think adequate for this essay, that the best account of the collective justification individual rights trump is a utilitarian account. That is a very popular account, and I use it, to suggest the logical character of claims about rights, here. But for a longer discussion of that character, see my remarks about rights and collective justification in my books, A Matter of Principle, particularly Chapter 17, and Law's Empire, particularly Chapter 8.

[2] Even if we conclude that no one can have any rights when he or she is demented, we might still decide that the rights he had when he was competent continue to have moral force. (We think, for example, that the rights of people now dead continue to have force, so that we are constrained, for instance, by promises we made to them when they were alive.) Indeed, I shall argue that the rights a demented person had earlier are crucially important. But the character of the rights we recognize as affecting how demented people must be treated will be affected, as we shall see in later sections, if we decide that the interests a demented person now has cannot themselves be protected by rights, because he is no longer the kind of being that can have rights. That is the issue of the present section.

[3] Reference to, e.g., Danto's discussion of this topic in the Encyclopedia of Philosophy.

[4] In this and the next section I use the names "Kantian" and "Humean" loosely, not to refer specifically to the views of Kant and Hume, but to describe general approaches to moral philosophy their names have been used to describe.

[5] Reference to Strawson, Freedom and Resentment.

[6] I do not consider (because this issue lies outside our general topic) how far this argument endorses or supports rights for animals.

[7] Reference to A Theory of Justice.

[8] Reference to the Dewey Lectures.

[9] See note x supra.

[10] See, e.g., John Mackie, Ethics.

[11] Reference to Parfit's examples of prisoner dilemmas and the moral solution.

[12] That is so even if these independent principles include a provision that no one may be a member of the moral community, even if a member of the political community, unless he can contribute to the scheme of co-operation morality creates. For someone who becomes demented could contribute earlier in his life and so, on the second version, did become and remains a member of it.

[13] I am assuming, in this discussion, that it can, at least sometimes, be in a person's overall best interests to force him to act otherwise than as he wants: that it can be in a person's overall best interests, for example, to be made not to smoke, even though we count the fact that his autonomy is to some degree compromised, considered in itself, as against his interests.

[14] There is an important debate in the economic literature on the question whether it can be rational to act against one's own best interests. The better view is that it can. See, e.g., Sen, Rational Fools, Philosophy and Public Affairs.

[15] Problems are presented, for this judgment of overall integrity capacity, when a patient appears only periodically capable of organizing his life around a system of desires and wishes. He may seem able to take command of his life sometimes, and then lapse into a more serious stage of dementia, becoming lucid again only after a substantial intervening period, at which time the desires and interests he expresses are very different, or even contradictory. It would be wrong, I think, to say that such a patient has the capacity for autonomy periodically: the capacity autonomy presupposes includes a capacity for stable desires seen as giving structure to a continuing life, and this is a capacity that cannot be displayed just considering each period of lucidity on its own. Some considerable integration of interests and projects among these periods would be necessary.

[16] I am assuming, in this contrast, that at least some cases of what the philosophers call weakness of will -- failing to abide by past settled convictions in a moment of great temptation -- are nevertheless exercises of autonomy. It would be, I think, a serious mistake to conflate these two different situations: when someone has the general capacity to bend his life to his convictions, and does not exercise this, and when he has become demented and so lost the capacity altogether.

[17] Reference to Massachusetts decision.

[18] We need this distinction, for example, to explain why mind-changing drugs or other forms of brainwashing that produce pleasure and contentment are not in their victims interests.

[19] For some purposes we would need a further distinction: a doctor acts in his patient's ex ante subjective evaluative interests when he improves his life judged by the patient's standards at the time the decision is taken, and in his patient's ex post subjective evaluative interests when he improves it judged by the patient's standards after the decision has had its effect.

[20] We shall have to consider the question of paternalism with respect to the demented later. I should add here, however, that the various distinctions between types of interests we have been canvassing allow an improved statement of the forms and degrees of paternalism. Any account of when paternalism is justified must attend to the differences between our stopping someone from taking drugs because we think he is ignorant of what the experiences that will follow will actually be like, or because we think it will lead to the kind of life he now disapproves, or because it will lead to the kind of life we but not he disapproves.

[21] Reference to some of these statutes.

[22] Reference.

[23] The most elaborate philosophical defense of this argument is provided in the libertarian literature; in particular in Robert Nozick's book, Anarchy, State and Utopia.Reference.

[24] I call this the "utilitarian" cost-benefit approach because other ways of measuring costs and benefits, different from the welfare calculations we associate with utilitarianism, might be designed, and some of these would appear to be more favorable to the demented. We might, for example, suppose that welfare improvements to those already worse off are to be weighted more heavily, in the overall calculation of costs and benefits, than welfare improvements to those who are already at a high welfare level. But any such special weighting would require a theoretical justification, which would provide good reasons not only for counting welfare improvements to the badly off as more important but also for weighting these in a particular way, and would therefore seem to presuppose one or another of the different approaches to the rights of the demented to resource I consider below.

[25] In this discussion I am assuming that the cost-benefit approach I am considering uses what is often called a hedonistic conception of welfare, that is, that it measures welfare in terms of experiential interests. Other forms of the cost-benefit approach use a different conception of welfare: that someone's welfare depends not exclusively on his experiential interests, but more generally on the degree to which his desires have been satisfied. I assume the hedonistic conception of welfare because that

seems to be the conception most often used in the medical literature. The cost-benefit approach would justify somewhat more resources for the demented on the demand-satisfaction conception than on the hedonistic conception, but not, I believe, significantly more.

[26] Reference to Robb. Importance of referral as screening.

[27] A philosophical basis for the welfare-floor approach might be found in the concept of fundamental "needs." It is a familiar claim, in political philosophy, that people have certain fundamental and crucial interests, and a right that these be satisfied by any community in which they live. Different versions of this claim identify different lists of basic needs, though the lists overlap considerably. Any version must justify the needs it takes to be basic, and this is often a source of difficulty. Most lists of fundamental needs include these: the need for food, shelter, education and medical care. But why, then, is satisfying employment not also a basic need? What test certifies the familiar list but excludes that need? The needs approach has even greater difficulty in defining the degree to which the needs it identifies must be satisfied. What kind of shelter does someone have a right to have in virtue of his need for shelter? How much education: why twelve years, say, instead of six or sixteen? How much medical care, providing what level of life-expectancy? The case of permanent dementia exposes these difficulties, again in a dramatic way. How does dementia affect needs? Does a demented person really need anything — what concept of need is in play if we say he does? How much and what character of custodial care does he need, and does he need to continue living the way competent people might be said to need that?

[28] This use of Rawls' theory would be an adaptation rather than a direct application, because he defines the "worst-off" group in terms of its holdings of "primary goods" rather than directly in terms of its welfare. (But since Rawls' counts capacities as resources, the demented would still have a claim to be the worst off group, under his theory unadapted).

[29] In the next several paragraphs, I am summarizing a long article, What is Equality? Part II, in Philosophy and Public Affairs, 1981. It begins in a very abstract though not empty proposition: that government must establish and supervise a system of property that treats each citizen as an equal, that is, with equal concern. It then offers an interpretation or conception of that requirement: a property system shows equal concern if no citizen envies the resources available to another citizen throughout his life, that is, if no citizen would prefer any other citizen's life-time assignment of resources to his own. It does not follow, if that envy test is met, that citizens will have the same welfare or well-being on any conception of utility, because one may be happier, or more successful on his own lights, than another even if their resources are, on that test, equal. The test does, however, require an account of resources, and it uses a generous account. Someone's resources include not only his wealth, but his physical and mental capacities as well.

His resources are not, however, regarded as including his important preferences about the character of his own life; they do not include his convictions, attachments, identifications and projects. This distinction is not based on any assumptions about how far a person is either psychologically or metaphysically free to choose these important preferences, or how far he can conceive himself disassociated from any particular set of them. (We must be careful, in judging how far someone is free deliberately to alter his attachments, or to describe himself to himself without reference to them, to notice the difference between two claims: that he can abstract, in these ways, from all preferences and attachments, which seems wrong, and that he can abstract from any particular preference or attachment, which seems much more plausible.) It is rather based on the role preferences of that sort play in his life, and in his judgments about whether he is better or worse off, in resources, than someone else. Convictions and preferences are not the objects of these comparisons, but rather the basis on which they are made. Someone who believes he must dedicate his life to an art, or that the fate of particular other people with whom he identifies or for who he feels special attachment is crucially important to him, will not normally count himself worse off than others who do not share these ambitions or attachments even if they make his life more arduous. He will normally count his life, if anything, better because he has realized and accepted convictions of that sort. Of course some of what might be called tastes or preferences do not play that role: I might be subject to an addiction, for example, that I wish I did not have. In that case, as philosophers have put it, my first-order preferences are condemned by my second-order values, and the tastes I wish I did not have but cannot drop do count, negatively, among my resources.

In the real world, an initially envy-free distribution cannot be maintained, for two groups of reasons. First, people differ, naturally, in their productive capacities, by which I mean their capacities to produce goods and services others will pay to have. The distributional defect that follows from these productive differences can be described in two ways, and they are not fully identical. I may, ex ante, envy your superior productive capacities as resources you have and I do not. Or I may, ex post, envy the greater wealth they have allowed you to produce. A just state will transfer wealth to reduce the resulting inequality, though, for various reasons I shall not discuss here, it cannot eliminate it. I have proposed, as the standard a just state will use to fix the level of such transfers, an elaborate hypothetical insurance exercise which imagines people insuring against failure to have productive capacities allowing them to produce a given level of wealth. The operation and plausibility of that hypothetical insurance for productive capacity is problematic, and described in my article in PAPA.

Second, people differ in what we might compendiously call their luck. In particular, some fall ill or are incapacitated in various ways whose harm is not limited to productive capacity. They then need more resources than others and are generally able to produce less. Once again the envy test fails, and a just state will seek to transfer wealth in partial compensation. The hypothetical insurance device is easier to understand and apply as a standard for that transfer. Imagine that insurance is available offering a choice of different levels of compensation, each at the premium that that level of compensation would command in an efficient insurance market. Imagine that we can determine, within reasonable limits, what coverage people would on average buy against particular illnesses or incapacities, for what average premium. We can model a system of taxation and redistribution on these results of the hypothetical exercise. The state must provide, in kind or in funds, coverage at that average level for at least those who cannot pay for it themselves, and it must pay for this out of taxation aimed to capture the equivalent of the premiums those who receive the benefits would have paid for that coverage in the hypothetical market. See the article in Philosophy and Public Affairs for more elaborate discussion. For a somewhat different account of an approach like the hypothetical insurance approach, see Norman Daniels. [Reference.]

[30] I shall later distinguish two versions of a practical program modeled on the hypothetical insurance approach. In the first, government provides coverage only for those who cannot afford the coverage level set by the hypothetical insurance exercise themselves, and collects taxes accordingly, allowing those who can afford that coverage to make their own provision. In the second government provides coverage for everyone, and collects taxes at a correspondingly higher rate. If private insurance is actually available, at rates and conditions like the hypothetical insurance, there is not much difference between the two programs. People who would not be covered by the more selective program will use the taxes they do not pay as premiums for their own insurance. In practice, the two programs would have very different consequences. I shall later argue that, at least in the special circumstances of dementia, the second program is more just.

[31] See earlier note.

[32] Reference to Phillipa Foot article on euthanasia in Philosophy and Public Affairs.

[33] That conviction is not obviously sound: it is arguable that these instincts would not be much weakened by a specific exception allowing for killing people whose continued life can have no value for them. But it is also arguable that the damage to these instincts would be greater, and harder to limit, than other commonly accepted exceptions to the general prohibition against killing, like the exception for self-defense, because it is also an exception to the more discrete and much more fiercely held opinion that doctors must never kill. These reflections are anyway academic: no general policy of killing the permanently demented should or could be adopted now.

[34] It might be suggested that the insurance model need only assume, with respect to prudence, that the insurer thinks he his acting out of prudential concern, and that this does not require that the insurer and the patient be the same person, but only that the insurance believes that they are. But I am assuming that no approach to the rights of citizens can be accepted as sound if it presupposes that people are making serious philosophical mistakes, so that the approach would have to be abandoned if the citizens it serves were better informed or thought more clearly. In any case, the assumption with respect to temporal coresponsibility is an assumption about facts not beliefs: the insurance model would seem unfair unless the insurer and the patient really are the same person.

[35] These twin and connected assumptions of prudential concern and life-straddling co-responsibility are even more pervasive, in the way we lead our lives, than these crucial third-person judgments suggest. We can just barely imagine a radically different communal way of life in which assignments of property, and legal and moral responsibility, were periodically extinguished or altered. But we cannot imagine abandoning prudential concern and co-responsibility in the first person, that is, abandoning the idea that important decisions must be made having regard for future stages as well as any present stage, and that future stages must share in the responsibility for these decisions, because these ideas are constitutive of living a life. (We noticed that fact earlier in this essay though in a different form: we noticed how the idea of autonomy assumes and employs a conception of the good of a particular person across a single life.) I do not mean that we cannot imagine people living so as to make the best of a series of life-stages each of whose value was strictly independent of the value of the rest, like a team of relay runners suddenly running independent races against the clock. But that a creature living like that would be living a series of lives in the same body; like the independent relay runners, he would be living as a group of different people.

[36] Thomas Scanlon pointed out, in Tanner Lectures delivered at Oxford University in May, 1986, that we do not withhold public contribution towards the treatment of lung cancer from those who were heavy smokers before they contracted that disease.

[37] That is the conclusion of Nagel, who believes that personal identity is carried by the brain as a physical entity.

[38] That is the theory of Locke and, though in a more sophisticated form, many of his modern followers.

[39] See Derek Parfit, Reasons and Persons.

[40] Except for what he calls the unimportant fact that the causal explanation of the psychological continuity is abnormal in one of the two cases.

[41] Parfit thinks physical connections unimportant, but some people might think they matter.

[42] It will seem plausible to many readers that in some circumstances co-responsibility should hold when psychological continuity has been preserved even though they are doubtful that identity holds. I have in mind this science-fiction case: suppose a murderer, about to be caught, arranges for an exact replica of himself to be created hoping to escape punishment by arguing that the replica and the (now extinguished) murderer are two different people. We might think, whether or not we ac-

cepted his claim that identity was broken by the replication, that the replica deserves to be punished anyway. Reference to David Wiggins' observation that people cannot escape punishment by contriving their own fission. (See the discussion below as to whether we should, in a case of this sort, regard identity as holding between the murderer and his replica. But no one would think the replica deserved punishment if the replication had gone wrong, and the replica had no memory of being the criminal. (Nor, of course, would the murderer have contrived the replication if he expected that result.)

[43] "Wired-in" suggests that these assumptions are genetically rather than culturally transmitted, which we can assume for this discussion because nothing turns on it.

[44] Comparison with re-incarnation. Brings out the possible need to distinguish two different concepts of a person.

[45] Parfit reaches the opposite conclusion about this case, mainly because he worries about the case in which I survive for an hour after the replica is created, and he thinks it impossible that "I" should be in two places at the same time as I then (briefly) would if we counted the replica as me. But, from the point of view of the assimilationist approach, the rule that I cannot be in two places at one time, applied in this strict way, is only another formula we need not accept. Of course, if the person being replicated survived for a substantial period, that would present a different case for the project of adjusting identity to the system of identity-grounded ideas I have been discussing, and we might well, then, decide that I am not my replica. I discuss that different case in the text just below. But it is central to the assimilationist approach that we need not treat automatically treat circumstances as different as those in which the person replicated survives a few minutes and survives indefinitely the same way.

[46] Compare Nozick's "closest connector" doctrine. The qualifications would probably apply in those cases, as in the first of Bernard Williams' cases I described earlier, when it would produce two different candidates for the continued identity of a single person

[47] I emphasize the relative character of the test the strategy uses because someone might think that it is, for reasons that might include a radical view of personal identity, always unjust, for example, to hold a later stage responsible for the acts of an earlier stage, even in what we call normal circumstances.